
January 2006

**The MISSOURI PLANNING COUNCIL
For DEVELOPMENTAL DISABILITIES
Statewide Needs Assessment**



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PREFACE

The Missouri Planning Council for Developmental Disabilities (MPC) is a federally-funded, 23-member consumer-driven council appointed by the Governor. Public Law 106-402 mandates that the Council is to plan, advocate for, and give advice as to programs and services for persons with developmental disabilities. The focus of such programs is mandated to increase opportunities for self-determination, independence, productivity, and integration into communities. The Council's mission is to support communities to include all persons with developmental disabilities in every aspect of life.

The Council is required by the United States Department of Health and Human Services, Administration on Developmental Disabilities to develop a five-year plan to guide its efforts in meeting the federal mandate. This plan must be based on data-driven strategic planning for advocacy, capacity building, and systems change related to the federal areas of emphasis: Employment, education, housing, transportation, health, childcare, quality assurance, formal and informal community supports, and recreation. Before completing the five year plan, the Council embarked upon a process to assess the extent to which services, supports, and other assistance are available or unavailable to individuals with developmental disabilities and their families. The comprehensive statewide needs assessment also assisted the Council in determining the extent to which individuals and families have the ability to access and use services provided in their community; participate in opportunities, activities, and events offered in the community; and to contribute to community life.

In order to carry out this multiyear task, the Council provided partial support to eleven Regional Advisory Councils and contracted with other developmental disabilities organizations in hosting 127 focus groups involving 975 participants. The focus groups were conducted in 110 of Missouri's 114 counties. Written surveys were also conducted involving 737 individuals. Both individuals with developmental disabilities and their families were represented in the focus group and survey participants. In addition, participants were selected to allow diversity in their geographic locations, the type of disability that they or their family member experience, the age of the individual with a disability, and whether or not the individual received services from the state service system.

The Council wishes to express its gratitude for the assistance of the Institute on Human Development, University of Missouri Kansas City; Regional Advisory Councils; and other entities and organizations, committed to serving Missourians with developmental disabilities in completing this needs assessment.

The five year plan developed from this assessment may be accessed at the Missouri Planning Council's web site: www.mpcdd.com or by calling 800-500-7878.

INTRODUCTION

In each of the eleven MRDD Regions in Missouri, people with disabilities and their families answered written surveys about different aspects of their life. This included employment, housing, recreation, and education to name a few. These surveys were conducted in all of the counties in Missouri. Table 1 lists the counties and the number of returns that were received from each of these counties. Counties not listed had no returns.

Table 1. Counties

County	# of Returns	County	# of Returns	County	# of Returns
Adair	7	Harrison	1	Pettis	6
Atchison	1	Henry	9	Pike	12
Audrain	7	Henry/Clinton	2	Platte	20
Barry	7	Hickory	2	Polk	7
Barry/Monett	1	Howard/Fayette	4	Pulaski	12
Barton	6	Howell	7	Putnam	6
Baryy/Cassville	2	Iron	6	Ralls County	7
Bates	8	Jackson	18	Randolph	7
Bollinger	7	Jasper	9	Ray	7
Boone/Columbia	9	Jefferson	15	Ripley/#5	4
Buchanan	17	Johnson	7	Saline	8
Butler #4	6	Knox	6	Schuyler	6
Caldwell	3	Laclede	10	Scotland	6
Callaway	7	Lafayette	9	Scott	7
Camden	8	Lawrence	11	Shannon	4
Cape Girardeau	6	Lawrence/Monett	1	Shelby	6
Carroll	8	Lewis	8	St. Charles	17
Carter	8	Lincoln	5	St. Clair	6
Carter/#6	1	Linn	5	St. Francois	12
Cass	6	Livingston	7	St. Louis City	8
Cedar	6	Macon	6	St. Louis County	16
Chariton	6	Madison	6	Ste. Genevieve	8
Christian	5	Marion	6	Stoddard	6
Clark	6	McDonald	6	Stone	3
Clay	9	Mercer	6	Sullivan	3
Clinton	5	Miller	3	Taney	2
Cooper	8	Mississippi	6	Texas	6
Dade	6	Moniteau	3	Vernon	6
Daviess	1	Monroe	8	Warren	6
Dekalb	3	Montgomery	3	Washington	10
Dent	5	New Madrid	6	Webster	9
Dunklin	8	Newton	8	Worth	4
Franklin	10	Nodaway	6	Wright	1
Gasconade	11	Oregon	4	Total of 737 returns	
Gentry	5	Osage	11		
Greene	12	Pemiscot	12		
Grundy	10	Perry	6		

Missouri MRDD Regions

Table 2 represents the number of written surveys returned by MRDD Regions. The region with the highest rate was Region VII with 12.8%. Region I had the lowest return rate (6.2%).

Table 2. Missouri MRDD Regions

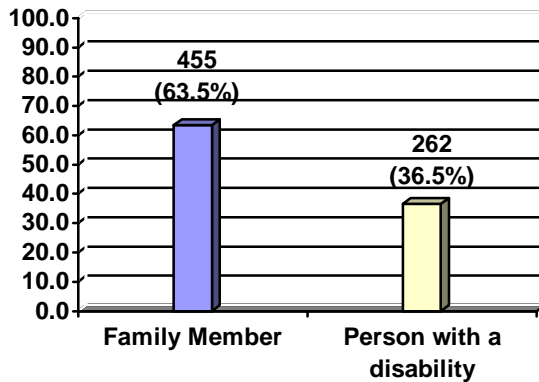
Region	Percent
<u>Region I: Albany - Council on DD</u> Counties served: Andrew, Atchison, Buchanan, Caldwell, Clinton, Daviess, DeKalb, Gentry, Harrison, Holt, Nodaway, and Worth.	46 (6.2%)
<u>MO Region II: Kirksville - Planning and Coordinating Council for DD</u> Counties served: Adair, Clark, Grundy, Knox, Lewis, Linn, Livingston, Macon, Mercer, Putnam, Schuyler, Scotland, Shelby, and Sullivan.	88 (11.9%)
<u>Region III: Hannibal - DDA Council of Missouri</u> Counties served: Audrain, Lincoln, Marion, Monroe, Montgomery, Pike, Ralls, and Warren.	54 (7.3%)
<u>Region IV: Kansas City - Metropolitan Council on DD (IV)</u> Counties served: Bates, Cass, Clay, Jackson, Johnson, Lafayette, and Platte, Ray.	84 (11.4%)
<u>Region V: Joplin - Council on DD</u> Counties served: Barry, Barton, Cedar, Dade, Henry, Jasper, Lawrence, McDonald, Newton, St. Clair, and Vernon.	86 (11.7%)
<u>Region VI: Springfield - Council on DD</u> Counties served: Christian, Dallas, Douglas, Greene, Hickory, Laclede, Ozark, Polk, Stone, Taney, Webster, and Wright.	51 (6.9%)
<u>Region VII: Rolla - Council on DD</u> Counties served: Camden, Crawford, Dent, Franklin, Gasconade, Iron, Maries, Miller, Osage, Phelps, Pulaski, St. Francois, Texas, and Washington.	94 (12.8%)
<u>Region VIII: Popular Bluff - Disability Council of the Ozarks (VIII)</u> Counties served: Butler, Carter, Dunklin, Howell, Oregon, Reynolds, Ripley, Shannon, Stoddard, Wayne.	48 (6.5%)
<u>Regional IX: Sikeston: Regional Council on DD (IX)</u> Counties served: Bollinger, Cape Girardeau, Madison, New Madrid, Mississippi, Pemiscot, Perry, Ste. Genevieve, and Scott.	64 (8.7%)
<u>Region X: Central Missouri - Council on DD</u> Counties served: Benton, Boone, Callaway, Carroll, Chariton, Cole, Cooper, Howard, Moniteau, Morgan, Pettis, Randolph, and Saline.	66 (9.0%)
<u>Regional XI: St. Louis - Gateway Regional Advisory Council (Region XI)</u> Counties served: Jefferson, St. Charles, St. Louis City and County.	56 (7.6%)

Written Survey Respondents:

The majority of the respondents (63.5%) were family members. There were 262 responses from persons with a disability (36.5%). Of the 737 that participated in the survey, 20 didn't respond to the question *I am a: family member or persons with disability*. Figure 1 presents these findings.

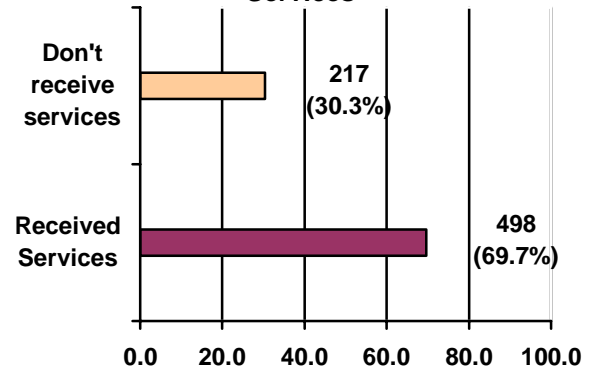
The majority of the respondents received services from the Division of Mental Retardation/Developmental Disabilities (69.7%). Slightly more than 30% did not receive these services. Of the 737 participants that returned the survey, 22 respondents didn't indicate whether they *received or didn't receive* services from MR/DD. (See Figure 2.)

Figure 1: Written Survey Respondents



Missing = 20

Figure 2: Respondents Receiving Services



Missing = 22

Focus Group Respondents:

In addition to the written surveys, 127 focus groups were held in 110 of Missouri's 114 counties (Multiple focus groups were held in the Kansas City and St Louis metro areas). There were 975 individuals who participated in the focus groups, 41% (400) were individuals with a developmental disability, and the other 59% (575) were family members. Slightly over two thirds (64%) of the focus group participants received services. The following summarizes the results of both the written surveys and the focus groups.

EMPLOYMENT ISSUES

Survey respondents were asked to rank where adults with disabilities work/live in the community. The options were (1) non-employment situations; (2) sheltered employment; (3) community employment with paid supports; and (4) regular job in the community. (See Table 3.)

Table 3. Most and Least Likely Place to Work

Item	Non-Employment Situation	Sheltered Employment	Community Employment with Paid Supports	Regular Job in the Community
Where do adults with disabilities work/live in your community	198 (37.3%)	224 (42.2%)	40 (7.5%)	69 (13.0%)
Where do adults spend the Least amount of time	66 (13.8%)	52 (10.9%)	41 (8.6%)	319 (66.7%)

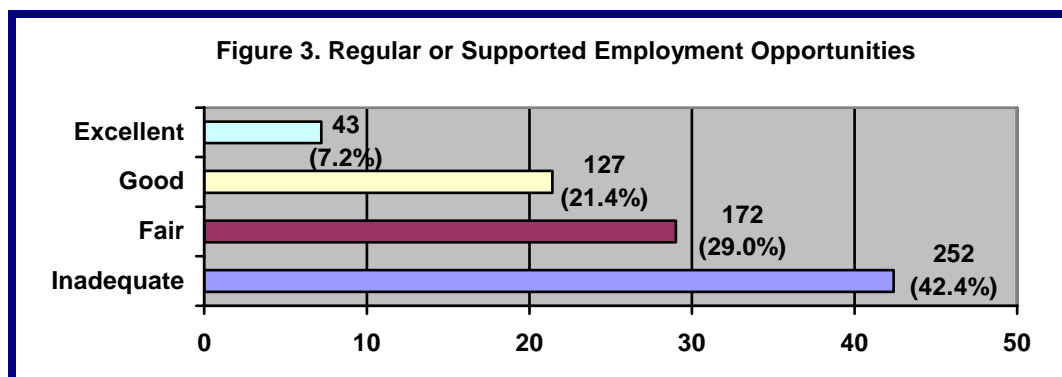
The respondents were also asked whether the different types of employment opportunities were (1) inadequate; (2) fair; (3) good; or (4) excellent. Table 4 presents the findings. Of the four employments options, sheltered employment services were rated as most

adequate (mean of 2.53), and regular jobs in the community were rated as least adequate (mean of 1.72).

Table 4. Adequacy of Employment Settings

Item	Inadequate	Fair	Good	Excellent	Mean
Regular job in the community (282)*	146 (51.8%)	79 (28.0%)	46 (16.3%)	11 (3.9%)	1.72
Community Employment with paid support (487)*	196 (40.2%)	136 (27.9%)	106 (21.8%)	49 (10.1%)	2.02
Sheltered Employment (558)*	118 (21.1%)	136 (24.4%)	193 (34.6%)	111 (19.9%)	2.53
Non-employment situation (446)*	167 (37.4%)	102 (22.9%)	113 (25.3%)	64 (14.3%)	2.17
<i>Scale: 1=Inadequate....4=Excellent *Total number responding</i>					

Figure 3 reflects respondents rating of the opportunities for regular or supportive employment for people with disabilities in their community. The rating was on a four-point scale (1=Inadequate...4= Excellent). Opportunity for employment in the community was seen as *fair to inadequate* by 72.8% of those who responded to the question.

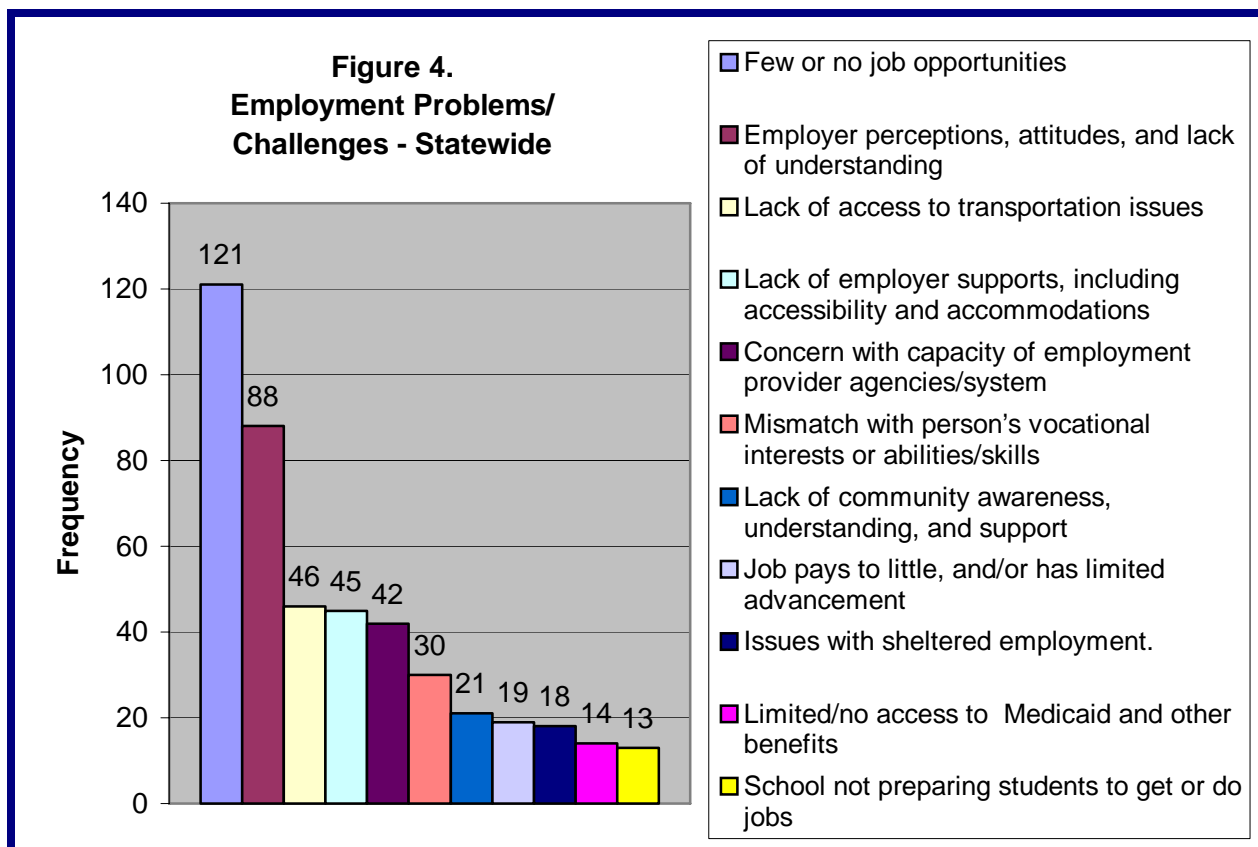


Employment Focus Group Discussion:

Focus group participants were asked to discuss the issues they have with employment, including: 1) the problems and challenges they have experienced in getting employment, and 2) the help and support they need to gain employment. Employment issues are listed below.

Employment Problems and Challenges:

Several focus group participants stated that there were *few or no job* opportunities (121 comments). Another theme related to employment problems and challenges frequently commented on was employer perceptions (88 comments). These themes are given in detail in Figure 4. Detailed comments related to employment problems and challenges are also found below.



Few or no Job Opportunities (121 comments):

Focus group participants stated that *there are not a lot of opportunities in the community* for jobs. One individual stated that there is *no employment for anyone with or without disabilities*. Comments by focus group participants about problems and challenges they face in finding a job are below.

Few Job Opportunities for People with Disabilities: Many of the participants in the focus groups commented there is no employment for individuals with disabilities. Many made statements about their own communities and the lack of jobs. One participant commented *I don't believe there are jobs for the disabled in Daviess County*. Another stated that *the availability of jobs for persons with disabilities is not adequate in Worth County*. Other comments about the lack of opportunities included:

- *There are not a lot of job opportunities in the county, we have to drive out of the county.*
- *A lot of people with autism are not being provided for in the county.*

Finding a Job: Some participants were *concerned about finding a job*. Another stated that finding a job was *like finding a needle in a haystack*. The issue of *getting a job is a concern*, because of *disability, lack of education, health issues and literacy issues*.

Lack of Jobs for Young People: Some of the focus group participants stated their concern over the lack of jobs for young individuals with disabilities. One stated *I don't have a job. We have three children and I am trying to find jobs for two of our children with disabilities as well as my wife.* Another commented that their young nephew, *never had a job. He needs a permanent place for employment. A barrier is knowing where to go to get connected to assist with employment.*

Employer Perceptions (88 comments):

The perception of employers about individuals with disabilities was a challenge commented on by some of the respondents. One individual stated that *although local employers are sympathetic, they appear unwilling to offer jobs to people with developmental disabilities, even when the person has marketable skills.* Other related comments are included below:

Fear of Liability: One problem with employer perceptions is that they are *reluctant to hire because of lawsuits.* One participant gave the example *my husband is handicapped. It is hard for him to find a job because they see him as a liability risk because he uses a wheelchair.* Another participant gave the example of her daughter who *because of her seizures, liability was an issue for public employment.*

Lack of Knowledge: There is a lack of knowledge about individuals with disabilities on the part of the employer. One participant in the focus groups stated that *there is a lack of knowledge about people with disabilities. If you don't have the knowledge you can't give them the jobs.* Another gave the example that *private companies do not have the understanding of developmental disabilities.* Another stated that *companies don't understand people with disabilities and how to hire them.*

Lack of Flexibility: Many individuals experience the lack of flexibility in employment. For example, *normal people have every excuse in the book for being late [to a job] but we can't make up excuses for that.* It is often difficult for individuals with disabilities to be on time because they may have to wait for a ride, or for help bathing or dressing in the morning. Another stated that *employers don't want to take the time to show them [people with disabilities] how to do a good job.* Employers may lack the flexibility in allowing people with disabilities to do a job at their own pace. One individual stated that *others say I can't work because I am slow at typing. I prefer to do a slow but accurate job.*

Transportation Issues (46 comments):

An ongoing problem for individuals with disabilities is transportation. Some individuals have *no transportation* at all. Others have issues with transportation schedules such as *workshop transportation, which only runs at 2 p.m. but some shifts don't end until 4 p.m.* Another individual stated, *I would like to get another job out in the community, the problem is the transportation. I need someone to take me to and from work.* A common problem is that transportation is expensive. One gave the example that *there is no affordable transportation at night.* Another said that the *cost of gas*, was prohibitive.

Lack of Employer Supports and Accommodations (45 comments):

The lack of accommodations and supports to work is a barrier for some individuals with disabilities. One participant stated *I can't think of any employment opportunity that will provide supports needed*. Another stated that *accessibility is a problem*. One focus group participant gave an example of the lack of accommodation, *in terms of my self, difficulty with volume control with phones. The volume does not go up enough for me to use the phone comfortably*. Comments about the types of accommodations and supports needed are included in detail below:

- *Making things adaptable, tax credits for modifications, making the workplace accessible.*
- *More training is needed on what is available for people with disabilities.*
- *Improve on the training to stay on the job.*
- *Employees might need ramps and continued supervision.*
- *It is hard to complete paperwork. Paperwork can be overwhelming.*
- *Schools might need ramps.*
- *More job training is needed to help my son be a better employee.*

Capacity of Employment Providers (42 comments):

There is some concern for the capacity of employment provider agencies. Several things may contribute to this, such as the *turnover in job coaches*, and the *financial situation in the country contributing to some problems right now*. Other comments about the capacity of employment providers are provided in detail below:

Lack of Job Coaching: Many comments were made that *there are not enough job coaches*. One reason might be that *there is a turnover in job coaches*. Job coaches don't seem to last, *sometimes job coaches fade away after a month*. An example was given to the lack of follow-up from the job coaches, *after a person is out in the community working; the person does not have the follow-up as needed, because eventually it goes away. I think it is a problem when the job coach is just following-up a few times a month*.

Lack of Job Training: There is a *lack of job training services* for individuals with disabilities. One focus group participant gave the example that *when an individual gets out of high school it is hard, but we need more opportunity and training*.

Not Enough Job Provider Agencies: One problem is the lack of job provider agencies in the regions. One participant stated that *there are not a lot of options or choices for families to go to for help with individuals with disabilities. Only one agency in this area provides this service*.

Vocational Rehabilitation Services: There were several comments made about Vocational Rehabilitation Services. One experience was that *processing through vocational rehabilitation takes too long, but they were helpful*. Another individual echoed this statement *Vocational Rehabilitation takes forever*. Another stated that *Vocational Rehabilitation Services are hard to work with*. One experience with Vocational Rehabilitation was that *they only wanted to send my family member to WalMart, and he was able to go to college. There is a lack of drive from the professionals*.

Vocational Mismatching (30 comments):

Some individuals have difficulty *finding employment options that work for different levels of abilities*. One focus group participant gave a personal example, *I want another job in the community, the one I have is not enough to show what I can do*. Another participant made the observation that *matching abilities with jobs is difficult. If not for the workshop, it would be difficult for them to work*.

Lack of Community Awareness (21 comments):

Some focus group participants noted a lack of community awareness as a challenge. There is a lack of awareness because as one participant stated, *as a community member, I don't see people with disabilities working in the community*. Another participant stated that the problem is *communicating and educating the general public about people with disabilities. Everyone isn't comfortable talking about a person with a disability*. Another respondent emphasized the *need for public relations and community awareness*. One reason for more public relations and community awareness is because *people don't understand how to work with us*.

Jobs Pay Too Little (19 comments):

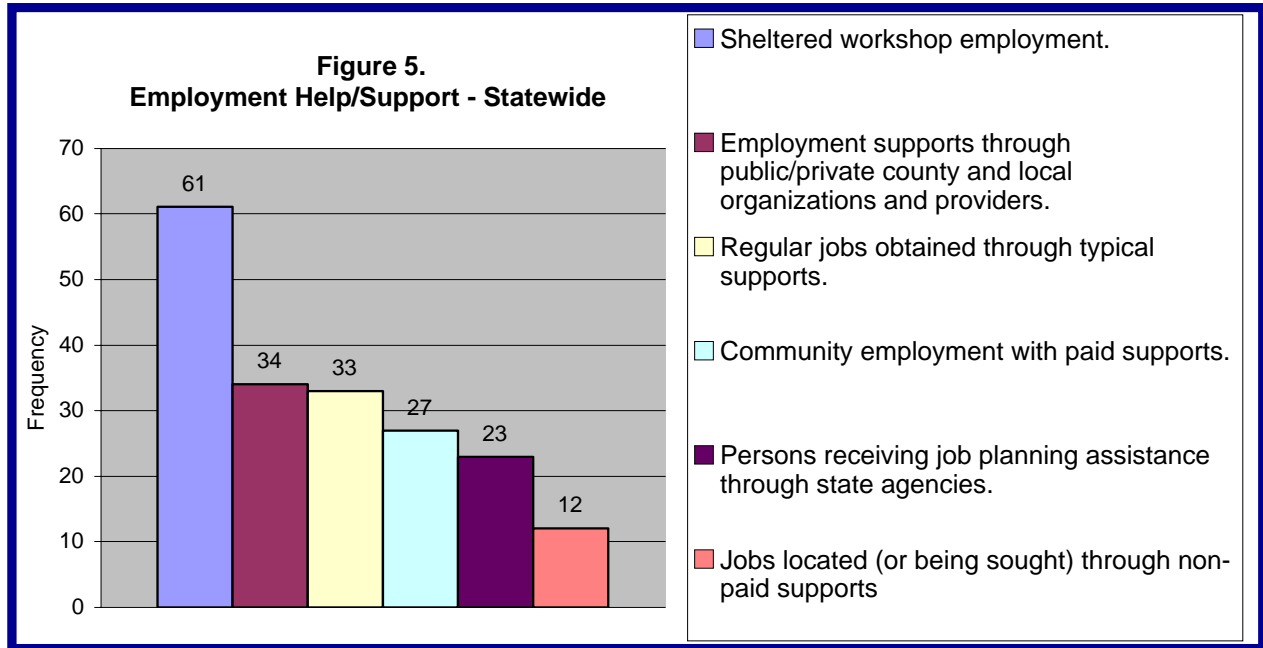
For some participants, *job pay is not adequate*. One individual gave the example that the *sheltered employment does not pay enough*. Some of the jobs provided are at minimum wage or below, *wages are low in Hickory County*. Another echoed this; *minimum wage paying jobs are all you can find*. Another stated that *the pay for employees at the workshop has been cut almost in half*.

Sheltered Employment (18 comments):

The work opportunities provided through sheltered employment are sometimes a problem. For example, *the workshop does what they need to do, but they don't go any further*. Another participant did not like the concept of sheltered employment because *workshops are nothing more than a warehouse. Supposedly the job is to assist and train people to get better jobs. They did not have those areas to address what skills truly are*.

Employment Help and Supports Needed:

Focus group participants discussed the types of employment help and supports they have experienced in getting and keeping jobs. These experiences included such things as sheltered workshops (61 comments), and employment supports from public and private organizations (34 comments). The themes and comments are given in detail in Figure 5. Detailed comments follow.



Sheltered Workshop Employment (61 comments):

Several commented on sheltered workshop as a needed help and support. For some, *help was given through the sheltered workshop*. One individual provided an example of how the workshop helped them, *I needed work desperately, and the workshop helped when I couldn't get a job*. Other comments about sheltered workshop employment are provided in detail below.

Enjoyable Work Environment: Focus group participants commented on how much they, or someone they knew, enjoyed working in the sheltered workshops. One participant was *very happy working at the workshop. I worked at it for 15 years*. Other individuals provide the examples; *my uncle worked at a sheltered workshop and seemed to like it*. Another added, *my daughter has worked at the workshop, and I thank God for the workshop. I thank Bates County for supporting it*. For one family member it has provided positive reinforcement. *My family member has been there for 10 years. They tell him he is a good worker. He enjoys it*.

Workshops Give People Something To Do: The sheltered workshops have helped provide many individuals with things to do, and give them a sense of belonging. One individual gave the personal example *I work as a volunteer and keep my self busy always. The workshop is the best place I have worked*. A family member stated that *the sheltered workshop has provided their family member with a place to be*. Another example provided was that the workshop has given a family member *a focus every day, and on the weekend. He really likes the workshop. He would not be able to have another job because he requires repetition*.

Supports from Public and Private Organizations (34 comments):

Focus group participants commented on the types of supports from public and private organizations. One individual stated that they had received help from *ARC of Ozarks*. *They are good to work for*. Another individual stated that *supported employment programs help*. Another discussed the fact that *job shadowing provided by Choices for People has permitted some employers to see how valuable handicapped employees can be. They can give them jobs after the shadowing ended*. Other organizations that have provided support in the past are included in detail below.

- *Developmental Center of the Ozarks.*
- *Senate Bill 40 helped me find my job and helped me with the interview process.*
- *Lakes Country Rehabilitation helps individuals get jobs in the community.*
- *The Learning Center assisted me in getting my job.*

Jobs Obtained Through Typical Supports (33 comments):

Some individuals with disabilities have found support from jobs obtained from typical support systems. Examples given by focus group participants included: *I have worked at Pizza Hut for 14 years. It is a good job. I have been there 6 years*. Another individual stated *I didn't hold down a job until out of college. A lot of jobs that college students have, I can't do because of my disability. I am a mental health professional (counselor). I can do that in my chair*. Another individual has *worked at Wal-Mart for a long time*.

Community Employment with Paid Supports (27 comments):

Supported employment has provided help and support for individuals looking for jobs. Some examples given included a family member with a *brother that cleans offices, works at justice center doing janitorial services. He had a lady coach to help*. Another individual shared a personal anecdote *I am only 44 and have had over 200 jobs. I have learned that if I don't do the job the way the employer wants, they will fire me. Supportive employment has helped me a great deal*.

Job Planning Assistance Through State Agencies (23 comments):

State agencies will provide support and help with job and career planning for people with disabilities. Some individuals received this type of assistance through *Vocational Rehabilitation*. One focus group participant gave examples of the help received; the *Department of Vocational Rehabilitation helped me get a job. The Regional Center Case Managers have been helpful*. Another family received assistance from the school *we have been everywhere looking for services for my son when he turned 18. The school has helped by discussing transition services from school to work*. Another individual stated, *I have five siblings with disabilities. They receive services from the Regional Center, Local Adult programs, and the Sheltered Workshop*.

Jobs Located Through Non-Paid Supports (12 comments):

Some focus group participants received help and support finding jobs through unpaid supports. One focus group participant provided the example that *parents helped me get my job*. Other individuals had similar experiences. One individual stated *I have worked at lots of jobs before I came to the workshop, and I didn't have any problem. I had family help me*. Another also had *family members that helped me to find a job. I had training in school. Vocation Rehabilitation has helped me. Other employees helped me find my job*.

RESIDENTIAL SETTING ISSUES

The next section examined was residential settings. The respondents were asked to identify where people with disabilities in their community were most likely to live: (1) a place of their own; (2) at home with family and friends; (3) group home; or (4) large segregated facilities. The majority (57.4%) noted that most were likely to live at home with family or friends. People with disabilities were least likely (5.5%) to live in large segregated facilities. Only (16.6%) noted that people with disabilities live in a place of their own. (See Table 5.)

Table 5. Most and Least Likely Place to Live

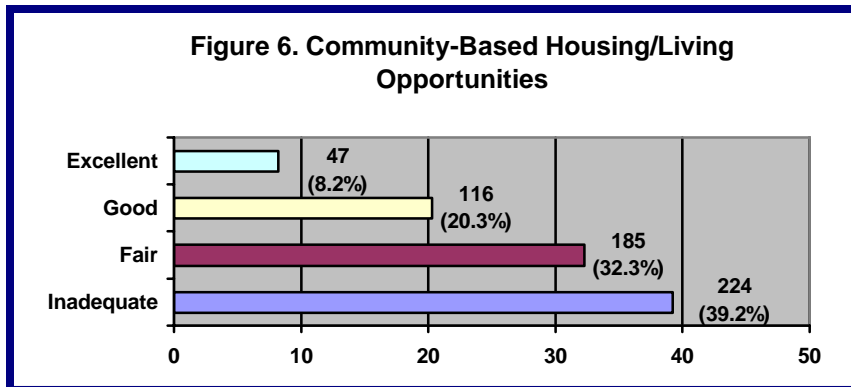
Item	Place of their own	At home with family/friends	Group home	Large segregated facilities
Where most likely to live	96 (16.6%)	332 (57.4%)	118 (20.4%)	32 (5.5%)
Where least likely to live	248 (47.6%)	27 (5.2%)	80 (15.4%)	166 (31.9%)

The availability of residential settings was assessed on a four point scale: (1=Not Available...4=Very Available). Of those who rated the availability of a *place of their own* (558), 26.0% responded as *not available*, while 54.8% indicated that they were *somewhat available*. The most available residential setting was *at home with family/friends* (Mean 3.09), with *group homes* being the next most available (Mean 2.40). Few respondents (10.6% of 444) indicated *large segregated facility* as being available. (See Table 6.)

Table 6. Availability of Housing/Living Settings

Item	Not available	Somewhat available	Most available	Very available	Mean
Place of their own (558)*	145 (26.0%)	306 (54.8%)	63 (11.3%)	44 (7.9%)	2.01
At home with family/friends (612)*	27 (4.4%)	102 (16.7%)	269 (44.0%)	214 (35.0%)	3.09
Group home (554)*	117 (21.1%)	198 (35.7%)	139 (25.1%)	100 (18.1%)	2.40
Large segregated facilities (444)*	234 (52.7%)	111 (25.0%)	52 (11.7%)	47 (10.6%)	1.80
Mean: 1=Not available...4=Very available *Total number responding					

Figure 6 shows how respondents rated the opportunities for community-based housing/living options. The rating was on a four-point scale (1=Inadequate...4= Excellent). Opportunity for community based housing/living was rated as *fair* (32.3%), or *inadequate* (39.2%) by over 71% of the respondents.



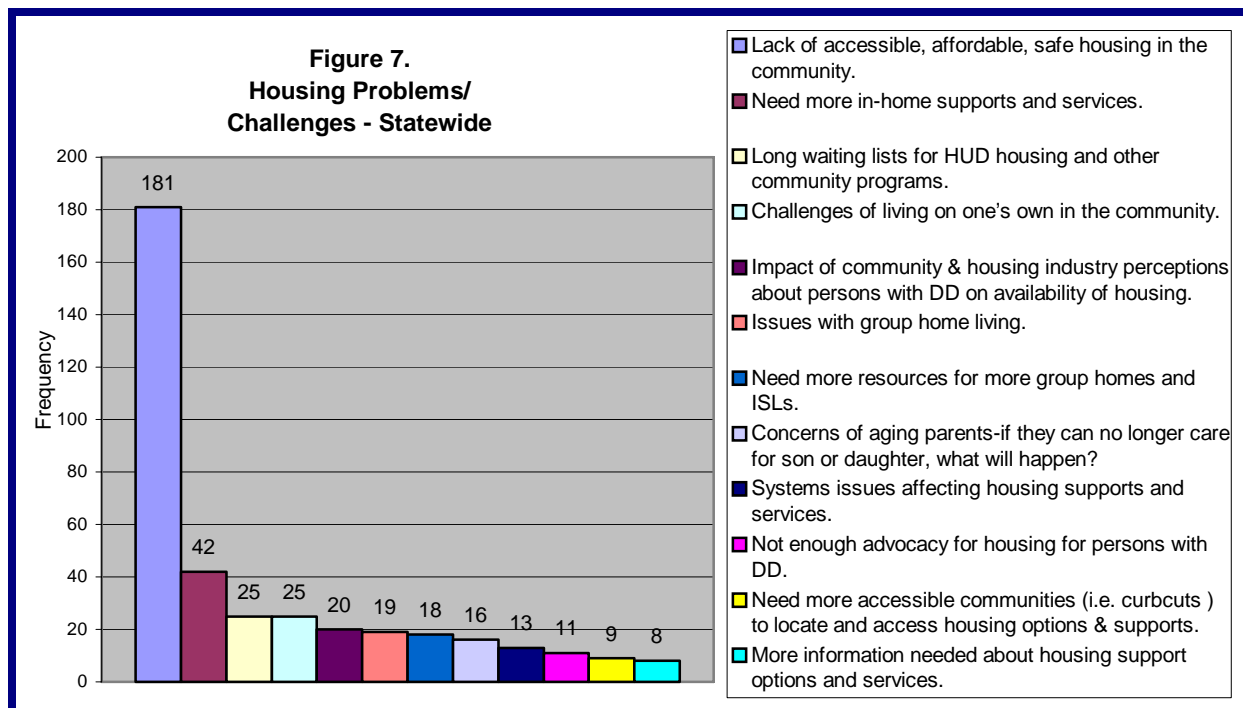
Housing Focus Group Discussion

Focus group participants from around the state discussed the experiences they have had finding, and keeping housing. The questions included: (1) Discussion of problems and challenges in

finding a place to live and (2) Help and Supports experienced in finding a place to live. Housing issues are discussed in detail below.

Housing Problems and Challenges:

Focus group participants discussed the problems and challenges they have experienced in finding a place to live. One problem commented on by several focus group participants is that more in-home supports and services are needed (42 comments). Long waiting lists for HUD (25 comments), and challenges living on one's own in the community (25 comments) were also common themes listed by the focus group participants. Themes are provided in detail in Figure 7. Related comments are also provided in the section below.



Lack of accessible, affordable, safe housing in the community (181 comments):

Focus group participants across the state agree that *housing is a big issue*. There is a lack of affordable accessible housing due to a number of reasons. Some simply *can't afford housing* or that *the rent is too high in my area*. Others stated that *there is not enough accessible housing* in their areas. Other comments related to the lack of affordable, safe, accessible housing are in detail below.

Fixed Incomes Limit Expenses: Many individuals with disabilities are on fixed incomes such as Social Security (SSI). This fixed income limits what people can afford in housing, and often rent or house payments are too high for individuals to find an affordable place to live. *There is no place where they can afford and be able to pay for it with SSI*. Illustrative of this is an example from one focus group participant: *because most people with disabilities have fixed incomes, we can't afford apartments and we are stuck. Even though I am working, I can't afford my apartment and I can't afford to move, either.*

Can't Afford Rent and Necessities: Several participants stated that they can't pay rents that are too high and afford other necessities, such as utilities. *The cheapest we could find was \$495 a month, social security is \$600 a month. That doesn't leave much for utilities.* Another individual added that *the cost of housing plus utilities is a lot more than most people with disabilities have, especially like this winter when heating costs are supposed to be so high.*

Lack of Housing in Area: Several focus group participants commented that *it is difficult to find housing* in their areas. One participant gave the example *the only place [that is affordable] is Questover in Urbana, but they have said there is nothing available.* Another individual stated that *there is no housing in my community, and if there was, people still couldn't afford it.* Another participant echoed this statement *there is none in our community. We must go out of our county to look for help with housing.*

Accessible Housing Inadequate: Focus group participants discussed the difficulty in locating housing that is accessible to them is a major difficulty for several reasons. Sometimes *what they call "handicapped accessible" is not always accessible. When new facilities are built, usually one or two apartments are truly accessible.* Others echoed this statement. *In accessible housing- sometimes the modifications are not adequate.* Another stated *if you need a home with accessible needs, then these homes aren't adequate.* Below are some examples that focus group participants gave of how accessible housing is not adequate.

- *Accessibility issues within apartments for wheelchairs.*
- *Physical limitations are in two story houses and bathrooms.*
- *The houses are not wheelchair accessible. The apartments aren't good for a scooter, but I can't get into bedroom or bathroom.*
- *The bathroom doors face the wrong way.*
- *Cabinets and vanities that are built too high for people in wheelchairs to use even in the disabilities accessible apartments.*

- *Lack of wheelchair accessible showers.*
- *Insufficient number and inadequate design for wheelchair ramps.*

Affordable Housing is Poor Quality: Many individuals that have been able to locate affordable housing discussed the poor conditions in which they often live. *A lot of the homes are not livable. One participant stated, we have holes, rates, and leaks the landlord will not help with that. Others echoed this statement people here have holes in their floors, ceilings, and roofs. It is awful. Others have trouble getting problems with their homes fixed sometimes my landlord has problems keeping the plumbing fixed. Others do not have air conditioning.*

In-Home Supports Are Needed (42 comments):

One problem and challenge for housing for individuals with disabilities is the lack of in-home supports. There are *no supports to live in independent housing*, according to one focus group participant. Other participants in the focus groups echoed this statement, one commented that there is *no assisted living here and it is a big need*. Other comments related to the need for in-home supports made by the focus group participants follow.

In-Home Supports Not Available for Higher Functioning Individuals: There are not enough supports for some higher functioning people with disabilities to live independently, though they may not need to be in a group home. One focus group participant commented *with individuals that are higher functioning, they are just left between the cracks...the lower the functioning the easier it is to put them in a group home.*

Not Enough Supports for Mentally Ill: Another population that does not always receive enough support to live independently, are those that have been dually diagnosed or that have a mentally ill diagnosis. Some of the focus group participants discussed the lack of supports. One family member discussed their sister's situation *my sister was denied access to Independent Supported Living within the last two weeks. She was diagnosed at 26 years with a mental illness, and already had a mental retardation diagnosis. Independent Supported living wouldn't take her because of that* (mental illness diagnosis). Another commented that *there is a need for direct support professionals but it is not available with the mentally ill population. People with mental illness have no rights, no choice.*

Lack of Funding for Supports: Some individuals have tried to get independent living supports but have not been able to because of lack of funding assistance. Individuals may not be eligible for funding, or the funds may not be available at all. One individual commented that they *tried to apply for Habitat for Humanity but didn't make enough money to get their help. Isn't that something?* Another participant commented that there were *not enough Medicaid waiver slots available to use for housing or respite*. Lack of funding assistance leaves some individuals in situations they do not want to be in. One participant gave the example *I am having problems with my family but have nowhere else*

to go. I would like help through Housing and Urban Development (HUD) funds, but they are not available, there are wait lists.

Not Enough In-Home Support Staff: There is a lack of qualified staffing for individuals eligible to live independently. One participant stated *I own my own home, but I have problems hiring help in my home. There is little availability of help. When I have hired people, they are not dependable. Maybe they will work one month and then leave.* Others have had similar experiences, *when you find help you have to wait two to two and a half weeks to get a report back. There is no employee pool to pull from. In the meantime, there is no one who can fill in.*

Support Staff Should Be Better Paid: One way to ensure better qualified staff is to raise pay scales. One participant commented *I am thinking about my child's future-the caregivers are on a low pay scale, and I am worried that they are unreliable. The job is hard, and their skill level should be higher.* Another comment from a focus group participant echoed this sentiment. *Support staff jobs should not be considered a low skill and low paying job.*

Long Waiting Lists (25 comments):

Individuals with disabilities trying to get housing assistance are unable to receive what they need because of long waiting lists. There are *lists a mile long for housing*. In some places the *waiting list for housing is six months to a year*. Other comments related to long-waiting lists follow.

Long Wait Lists for HUD Housing: The Housing and Urban Development (HUD) wait list is two years. One family member gave the example *my son tried to get into HUD housing. It took forever to get in there. The waiting list-I know they have to wait, but it still takes a while, especially when you need it right away.*

Lack of Services: The long waiting lists for housing make it difficult for those in need in the interim. Some take what they can get for housing rather than wait. A focus group participant gave the example *it depends on who you are. There is a section for elderly, young people, people with kids. You take it or go to the bottom of the list, even if it is not desirable to live in.* Others do not have the choice because waiting lists are so long. *The only people getting housing or resources are if they are in crisis. There are no more subsidies for housing unless someone dies. It is like pulling teeth. Housing and homelessness are big issues. But there is nothing that can be done. People are living in their cars.*

Challenges of Living Independently (25 comments):

For many individuals with disabilities *it is tough living on one's own*. Many families worry about the issue of safety and proper supports for their family member to live independently. Comments related to the challenges of living independently are provided in detail below.

Limited Choices for People with Disabilities: Some individuals with disabilities report that they struggle with family members to make their own choices, including being given the choice to live independently. For example, one self advocate reported that he would *prefer to live on his own, as opposed to living with his sisters when his mother passes away. That is the plan right now*, however, he reports that *he does not always get along with those sisters*. Another finds it *hard to move out of my brother's house to Rainbow Village*. Sometimes there are limited choices in housing for people with disabilities. One focus group participant gave the example *my problems have been the limited choice of roommates*.

Challenges for Family Members: Independent living also poses challenges for family members of people with disabilities. Many families worry about their family member's ability to make decisions, about safety, and supports for independent living. One family member gave the example that *my son wants to live on his own, but we [parents] are not really sure he can handle it*. Another focus group member stated they were concerned for a family member because *I am worried about him getting proper support when he moves out. He can't live alone for safety reasons, and will there be proper support when he is ready?* Others worry that their family member cannot make proper decisions. One participant gave an example about their family member's lack of decision making skills, *Concerned Care got her an apartment in the inner city. People were walking in and out of her apartment. She did not see any danger in that. Then, the police picked her up in a bad part of town on night. She has no concept of danger. Our family is concerned about her safety*.

Impact of Community Perceptions on Housing (20 comments):

Community perceptions about individuals with developmental disabilities can have an impact on housing availability. *Attitudes are a big issue*. One focus group participant gave the example that the *community says "not in my backyard"*, and it is difficult to get housing. Other times, landlords and other housing authorities discriminate against people with disabilities. One participant has *a child with behavioral issues, and landlords discriminate against us, and we won't get in*. Sometimes *folks who look normal are a challenge because people expect them not to act out*. Education about housing rights would be helpful in combating community and landlord perceptions. A participant in the focus groups commented that *Section 8 housing has some slumlords. People should learn about their rights and how to file complaints*.

Issues with Group Home Living (19 comments):

It is often a difficult choice for families to send or to allow their family members to live in a group home. One parent discussed their concerns about group home living and its impact on their son. *My son moved into a group home. It was the hardest thing of my life. My husband was against it. I wish there was more availability for him to learn more independent skills. It is lost in a group home. I want him to grow and progress*. The parent also wanted to *make sure I point out that I love Hamilton House, and the staff there*. Residents often don't feel safe in their

surroundings. *You can't walk alone. You need to have a buddy.* Others agreed *you have to protect yourself* in the group home setting.

More Resources are Needed (18 comments):

More resources are needed for more individualized supported living and group homes. Several participants stated that there are *not enough group homes*. Sometimes *it seems like the group homes are too full* according to some focus group participants. Others stated that there is a *lack of resources for individualized supported living (ISL)*. In particular there is a *lack of group homes and ISL services for women*. The funding and other types of resources may also be lacking. One focus group participant gave the example *we tried to find ISL for my daughter. It was hit and miss. The funding was there, and then it wasn't.*

Concern for the Future (16 comments):

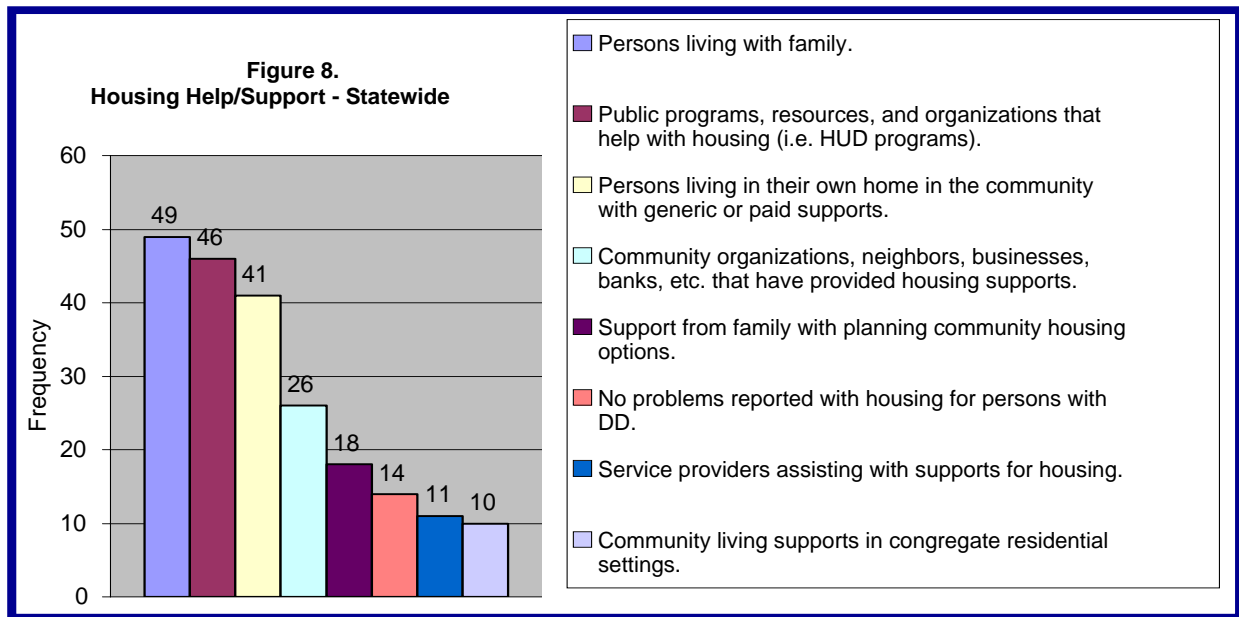
Some of the focus group participants voiced their concerns about their futures. In particular, concern for aging parents-if they can no longer care for children as one participant commented, *the primary concern is where will the disabled go after their parents are dead?* One parent stated *my son lives with me but I am concerned about his care when I am gone*. Another parent stated *it is important to know your child will be taken care of if parents pass away*.

Systems Issues that Effect Housing (13 comments):

The systems in which individuals must operate sometimes pose challenges. Particularly challenging is managing the funding that is given for housing and other expenses by governmental entities. One participant gave the example that a family member *cannot pay full rent and utilities because she is currently on spend down (Medicaid)*. Other focus group participants voiced concerns over Medicaid cuts, *if Medicaid cuts go through, the expenses will be unmanageable*. The cuts in Medicaid cause a backlash of issues. One participant gave the example that *the Medicaid Waiver has been our biggest difficulty. Half of our Social Security is gone because of spend down amount with Medicaid*.

Housing Supports:

Focus group participants discussed the types of supports they had received with housing. Several stated that they were living with their family (49 comments). Another theme related to housing supports was the support of public programs and resources (46 comments). Themes related to housing supports are included in Figure 8. Illustrative comments related to the top common themes are also provided in detail below.



Living With Families (49 comments):

Many of the focus group participants stated that they use family as a support. *Most people still live at home with their families.* One parent at the focus group stated that it was *no problem* for them. *Our son lives with us and he is happy.* Another focus group participant stated that while there are other community supports many still stay with their families. *The Senate 40 Bill has two Individualized Supported Living centers in the community, but most of the consumers still live at home.* Several parents have family supports set up for their children, one parent stated that *my son is taken care of when we are gone. We have the papers drawn out. Family will help him.* Other comments related to family support are below:

- *Children (even after adulthood) live at home because parents want them to.*
- *I live with my parents. I like having my own room.*
- *I live with my parents and I enjoy it.*
- *I live with my grandparents.*

Public Programs for Housing (46 comments):

Public programs give a lot of support for housing. One participant stated that the *Regional Center and Senate Bill 40 Board supports my living arrangement and helps me to look at other options of my choosing.* Another individual stated that *housing was available at Senior Housing. I couldn't live on Social Security Insurance.* One individual commented that there were several options in their community for housing. *Our community has several options for housing. Group homes, apartments, and most are accessible. The Independent Living Center does the best they can to try to help individuals find housing.* Other comments about public programs that support housing are below.

- *The HUD 811 program is very inexpensive. HUD puts up the 40% match and receives 60% federal dollars. Residents are only charged for what they can pay.*
- *Government Housing in Seneca is good.*

- *The Moniteau County SB40 Board has a steering committee that is looking into building a new group home.*
- *Richland Housing Authority has been very good in helping some of the people in this area get into affordable housing.*
- *Osage County Special Services has funds available through Emergency Assistance that will help clients fund renovations to make a house accessible.*

Individuals In Their Own Homes with Generic or Paid Supports (41 comments):

Several focus group participants discussed living in their own homes and the types of supports, such as generic (from family or friend), or paid supports. One focus group participant stated that *Individualized Supported Living should be available for everyone. It is a great program.* Another focus group member discussed the fact that they were able to purchase their own home and make it accessible. *I was really lucky. I found a home with an attached apartment and I put a ramp on it. There are two individualized supported living (ISL) providers in the county.* One self advocate living at home has someone come to her home once a week for a few hours to help with reading mail, bills, making appointments and phone calls, she just needs this type of support. Other types of living arrangements in the community that the focus group participants commented on follow.

- *I have a trailer. I am buying it.*
- *Case management services are available and most people served live in their own homes.*
- *I live in a house previously purchased by my mother. I live upstairs, and my brothers live downstairs.*
- *I have an apartment attached to my parents home.*

Community Provides Support (26 comments):

In some regions, the community at large has been very helpful. This includes community organizations, neighbors, banks, and businesses. *The community has made efforts to make housing accessible.* One individual at the focus group was able to get a loan and built a house from the ground up so it was accessible for my needs. Another individual discussed the fact that *Habitat for Humanity just built two homes, one for wheelchair [accessible] and the other for someone with a vision impairment.* Some of the participants talked about the fact that their *landlord is nice and is good about fixing things.* For one individual, *my trailer court has a good landlord, and he helped me find a cleaning lady.*

Support From Family with Planning Housing Options (18 comments):

Many individuals receive help planning their housing options from their families. One example is that *the family often helps people get apartments and assistance.* Another focus group participant provided an example *some families are doing things like buying a home for their adult child to live in with paid staff.* One individual stated *my parents helped my find My Place residential facility.*

TRANSPORTATION ISSUES

The next area that was discussed on the survey was transportation issues. Four types of transportation were examined: (1) special transportation; (2) public transportation; (3) family and friends; and (4) self-transportation. Very few noted that people with disabilities in their community were likely to use self-transportation (4.7%). Most respondents reported that the most likely use was public transportation (47.1%). (See Table 7).

Table 7. Most and Least Likely Transportation Choice

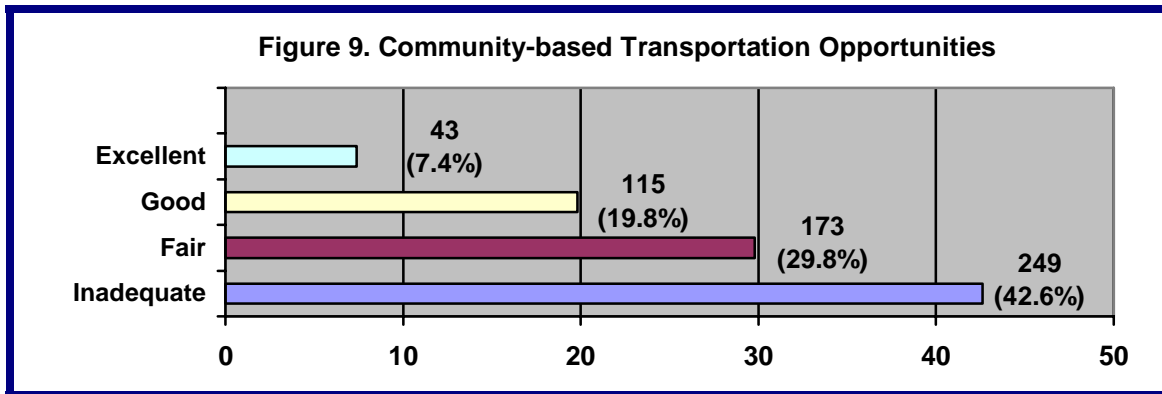
Item	Special Transportation	Public Transportation	Family and Friends	Self-transportation
How do people get around	115 (20.2%)	268 (47.1%)	159 (27.9%)	27 (4.7%)
Least likely	197 (38.6%)	48 (9.4%)	76 (14.9%)	189 (37.1%)

The adequacy of transportation options was assessed on a four-point scale (1=Inadequate... 4=Excellent). All four options were rated as *fair*, or a little above *fair* by the respondents. Of those rating *special transportation*, over 49% rated it as *inadequate*. Of those who rated *public transportation*, over 61% felt it was either *inadequate* or *fair*. While *self transportation* received an overall rating of *fair* to *good*, 36.8% rated it as *inadequate* and 36.1% rated it as *excellent*. Table 8 presents the findings.

Table 8. Adequacy of Transportation

Item	Inadequate	Fair	Good	Excellent	Mean
Special transportation (549)*	273 (49.7%)	103 (18.8%)	73 (13.3%)	100 (18.2%)	2.00
Public transportation (636)*	157 (24.7%)	233 (36.6%)	187 (29.4%)	59 (9.3%)	2.23
Family and friends transportation (555)*	141 (25.4%)	133 (24.0%)	156 (28.1%)	125 (22.5%)	2.48
Self transportation (418)*	154 (36.8%)	67 (16.0%)	46 (11.0%)	151 (36.1%)	2.46
<i>1=Inadequate...4=Excellent *Total number responding</i>					

Figure 9 shows how respondents rated community-based transportation opportunities for people with disabilities. The rating was on a four-point scale (1=Inadequate...4= Excellent). Opportunity for community based transportation was rated as *fair* (29.8%), or *inadequate* (42.6%) by over 72% of the respondents.

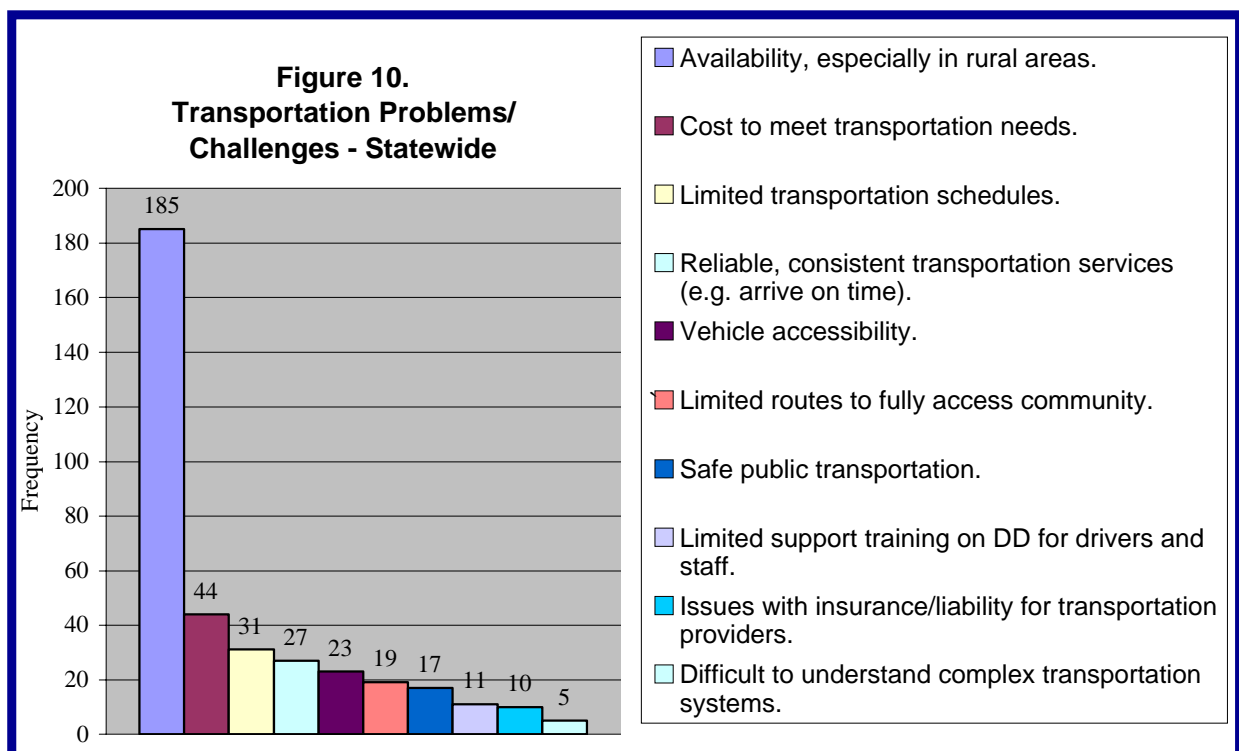


Transportation Focus Group Discussion

The focus group participants discussed issues surrounding transportation, including: (1) problems and challenges experienced; and (2) helps and supports received. Issues that concern transportation for individuals with disabilities are in detail below.

Challenges and Problems with Transportation:

Focus group participants made several comments about the availability of transportation in their areas (185 comments). The cost to meet transportation needs was also commented on (44 comments). Common transportation themes from the focus groups are in detail in Figure 10. Illustrative comments of the top common themes are also provided in detail below.



Availability of Transportation (185 comments):

Several focus group participants commented on the availability of transportation, particularly in rural areas. *Availability is lacking in the small rural community.* There is often no transportation, or the transportation available is not accessible to many with disabilities. One focus group participant commented, *I don't know what is worse, living in a small town, or a big town. They have Cal-a-Ride in Kansas City. I wish they would start a program here like that.* Comments related to the lack of transportation are in detail in the section below.

No Transportation: In many rural communities *there is no community transportation such as buses or cabs.* Another commented that there is *no transportation* in their rural area, *and it pretty much isolates you.* In many rural communities family members are the only means of transportation. One participant stated that *right now, we just don't have anything. It is just mom that takes her [places].* Others must rely on transportation from neighboring towns or areas. *My son goes to therapy, and we use the Medicaid transportation system. Instead of using a local driver, they call someone from a town 45 minutes away. They drove all that way to give us a ride across town.*

OATS is the Only Service: In some rural communities, *the OATS bus is the only transportation* for individuals with disabilities. This means of transportation is somewhat limited, *the only public transportation is OATS and it is only for medical appointments and shopping.* Because it is sometimes the only means of transportation, individuals may not be able to utilize it. In one community, *they do not have a taxi service and OATS is usually booked with appointments for senior services.*

Transportation is not Accessible: Some communities can provide public transportation options, but they may not always be accessible, or appropriate for individuals with disabilities. In one community *there is a low number of disabled, so it doesn't pay for transportation to come here or to be made accessible.* In other communities *there is not 24 hour transportation available or handicapped accessible.* Another community was only able to offer inappropriate transportation. *Transportation that was offered to my 4 year old was a Vo-Tech bus and that had high school kids on it.*

The Cost of Meeting Transportation Needs (44 comments):

Transportation in many communities is very expensive. Focus group participants stated *there is no affordable transportation.* Many participants commented that *gas prices affect how much we can travel.* One participant gave an example *you have to schedule a trip to Poplar Bluff, and it costs \$8.00, and then there has to be a group of people going. You can't just go as you wish.* The cost of gas has limited the amount one family member can work. *Our child tried competitive employment, but taking the time off work to get the child to and from work, and with gasoline prices being so high, the cost was more than the paycheck.*

Limited Transportation Schedules (31 comments):

Focus group participants commented on the limited transportation schedules. One participant stated that there were *no evening or weekend hours and hours are very limited.* In

order to receive transportation many individuals have to schedule it in advance. *For an accessible bus, you have to schedule two weeks in advance. If you miss, you still have to pay. The effect of this for many is that you can't be spontaneous because it is so hard to set up transportation-it takes too many calls and too much red tape to get something arranged. A lot of the accessible transportation such as the OATS bus have limited schedules.*

Lack of Reliable Consistent Transportation (27 comments):

Focus group participants commented that they *just wish transportation was more reliable*. Another added *when I find someone to take me somewhere, they don't always pick me up*. Another problem is that *sometimes they [transportation] are late to get you or they pick you up at the wrong place*. In another community, *the bus does not run as well on the weekend. You have to work with the bus system because they sometimes forget me. It does cause trouble with work. Weekends are my biggest problem.*

Vehicle Accessibility (23 comments):

In some communities *there is not enough accessible transportation*. There is *nothing available in school buses* for children with disabilities, stated one focus group participant. Public transportation is not much better, *there are no buses with wheelchair lifts, or no taxi service has a lift for a wheelchair*. One participant would like to see *cab companies buy some accessible vans*. One example of a local transportation service's lack of accessibility was given by a participant. *We have "Way To Go", but I would not call that public transportation. It only has certain stops and is not easily accessible.*

Limited Routes (19 comments):

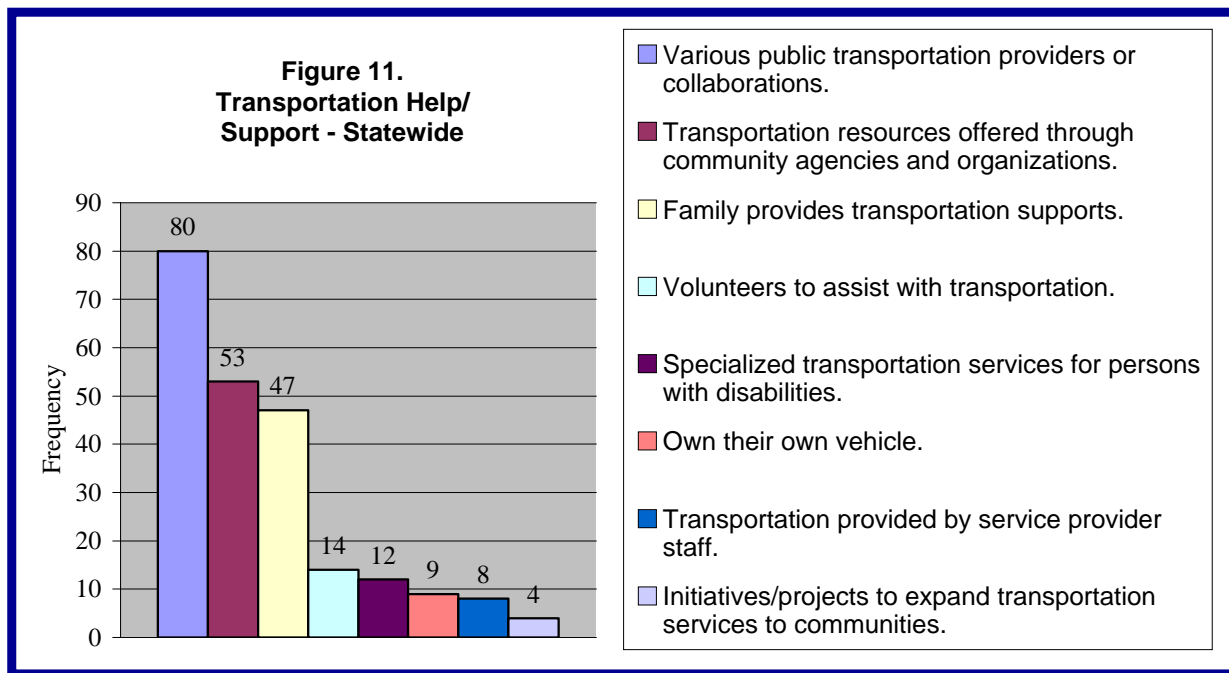
Transportation in some places is limited only to what is on its "route". Focus group participants gave examples of this. One stated that *the Platte County van will not transport [our family member] to Tri-county day rehabilitation because it is in Clay County*. Another family member stated *the school buses don't go down our road anymore*. Other focus group participants stated that *you may have to ride a designated route*.

Safe Public Transportation (17 comments):

Focus group participants had concerns that public transportation wasn't always safe. Some of the parents in one focus group called public transportation *"not safe, no supervision, terrifying"*. Many of the participants said *the bus is definitely not safe at night*. Another participant commented that *parents are children's chauffeurs. The bus is too far, it is not safe to walk that distance. The bus ride itself is not safe. There is no reliable safe transportation. You need door to door service to be safe.*

Transportation Helps and Supports:

The focus group participants discussed the types of help and support they had received for transportation. Several participants commented on the various types of public transportation providers and collaborations (80 comments). The common themes from the focus groups are presented in Figure 11. Illustrative comments are also provided below.



Public Transportation Providers or Collaborations (80 comments):

Focus group participants listed the types of public transportation providers in their communities. Participants also discussed the types of collaborations they utilize in order to get where they need to go. In many communities *most individuals take the OATS bus*. One participant commented that *the taxi system is helpful, dependable, and there are nice drivers*. Another participant provided an example of how they collaborate with other modes of transportation. *We take her to Lazy Lee's convenience store in Norwood, and the workshop picks her up there. Then they pick her up at work and bring her home. They prefer her to ride the bus to build independence.* Other types of transportation providers and collaborations are below.

- *I catch the bus, walk, I take the cab sometimes.*
- *We never had problems because we take [our family member] everywhere. The trade center also bent over backwards to help.*
- *Development Center is great. It provides services that are very accommodating.*
- *The Sunshine Bus transports to the grocery store and some workshops.*
- *We have three forms of transportation in Howell County. They will take you where you want to go if you can set up an appointment. Parents can get reimbursed by Medicaid.*

Transportation Services Offered Through Community (53 comments):

There are some transportation options offered through the community for families of people with disabilities, as well as for people with disabilities. In one community, *the Council of Churches will help in case of emergency*. One participant stated that in their community, *transportation is available to workshop and day program. The Senate Bill 40 Board picks up the transportation*. In other communities, *some churches will arrange for transportation to and from services*. One person stated *I bought a retired OATS van to be able to transport wheelchairs. I ended up transporting other students for the school. The school paid me and I transported their students with disabilities*. Other types of services offered through the community as listed by focus group participants include:

- *School district offered special bus to ride.*
- *Pettis County Community Partnership for transportation.*
- *The State School in Jefferson [City] brings a school bus to Osage County to pick up students.*
- *The Variety Club has offered some support.*

Family Provides Transportation Supports (47 comments):

Family members provide transportation supports for many of the focus group participants. One family member stated, *we have a van, we crimped to save for a lift, it took a long time to get a lift. We live way out in the country. There is no transportation here*. One member stated *my mom takes me everywhere*. Another comment was *I depend on myself or my family to get my son where he needs to go*.

Other Comments:

Some other illustrative comments include the following:

- *Link is available, but it is stretched to the maximum.*
- *There are only a few cab companies in the county.*
- *Help fund vehicle modifications and test for people with disabilities to get their own transportation.*

CHILDCARE ISSUES

Respondents were asked to identify the childcare option used most and least in their community by families who have a child with a disability. The childcare options given in the survey included: (1) regular childcare; (2) segregated or special childcare; and (3) family or friends. Most noted that *family or friends* were the *most likely* choice for childcare (69.6%). Few (12.6%) saw *segregated or special childcare* as the *most likely choice*, and almost 50% saw *regular childcare* as the *least likely choice*. (See Table 9.)

Table 9. Most and Least Likely Child Care Choice

Item	Regular childcare	Segregated or special childcare	Family or friends
Most likely childcare	86 (17.8%)	61 (12.6%)	337 (69.6%)
Least likely childcare	215	181	43

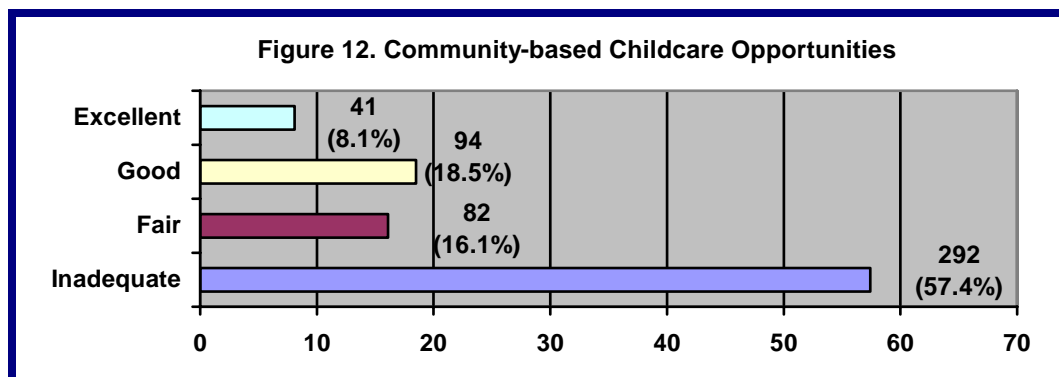
	(49.0%)	(41.2%)	(9.8%)
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The adequacy of childcare options was assessed on a four-point scale (1=Inadequate... 4=Excellent). The lowest rating was for *segregated childcare* which received a mean rating of 1.75. Over half of the respondents rating this option, rated this setting as *inadequate*. The highest rating was for *family childcare* (mean of 2.83). Over two-thirds of those rating this option, rated this type of childcare as *good* or *excellent*.

Table 10. Adequacy of Child Care

Item	Inadequate	Fair	Good	Excellent	Mean
Regular childcare (484)*	198 (40.9%)	153 (31.6%)	112 (23.1%)	21 (4.3%)	1.91
Segregated childcare (461)*	244 (52.9%)	114 (24.7%)	76 (16.5%)	27 (5.9%)	1.75
Family childcare (507)*	40 (7.9%)	119 (23.5%)	234 (46.2%)	114 (22.5%)	2.83
Scale: 1=Inadequate...4=Excellent *Total number responding					

Figure 12 reflects how respondents rated the opportunities for community-based childcare for families with a child who has a disability. The rating was on a four-point scale (1=Inadequate...4= Excellent). Opportunity for community-based childcare for children with disabilities was rated as *inadequate* by 57.4% of the respondents, and *good* by 18.5%.



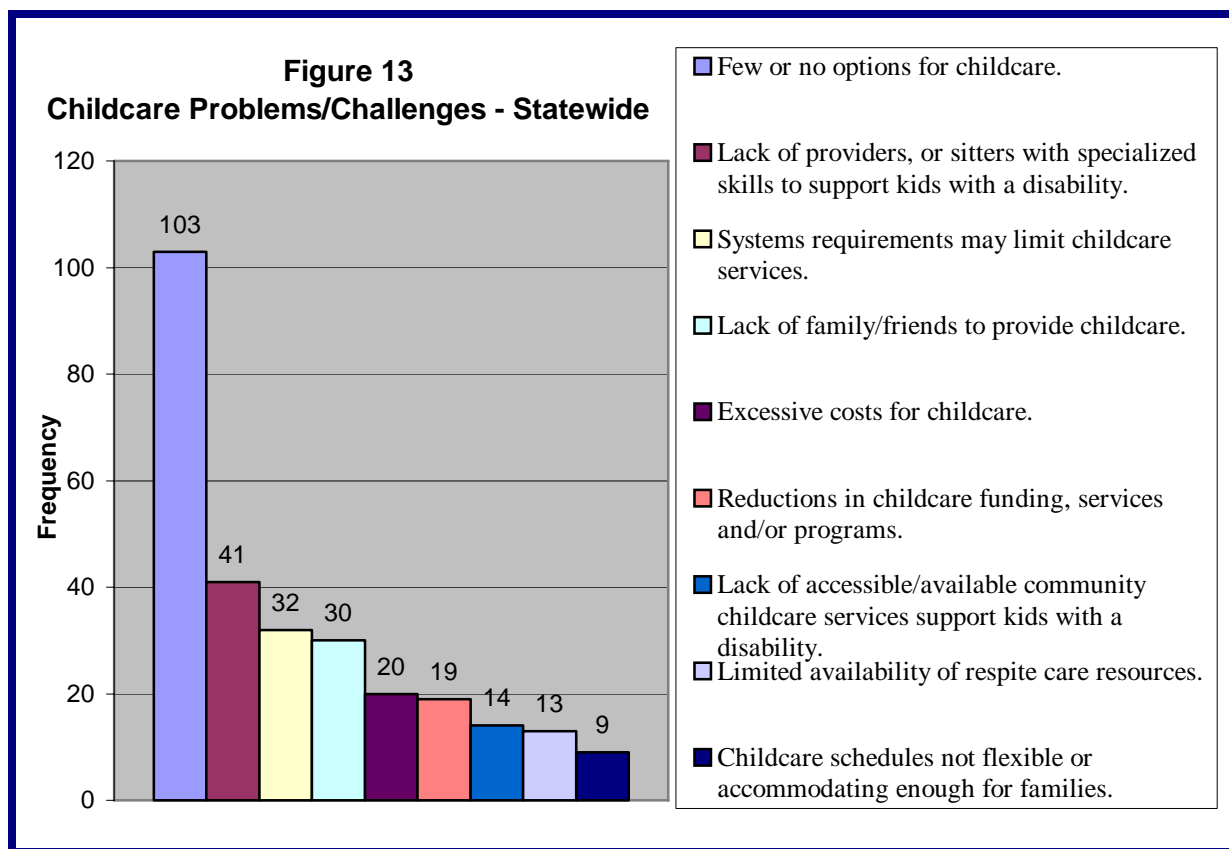
Childcare-Focus Group Questions

Focus group participants discussed the challenges and problems they have experienced finding childcare for their family members. The helps and supports family members have received for childcare were also discussed. This section presents the childcare issues and experiences of focus group participants in detail.

Childcare Challenges and Problems:

Family members discussed the challenges and problems they have experienced in obtaining childcare for their family member with a disability. One common theme among the participants was the fact that there are few or no options to childcare (103 comments). Common

themes discussed by focus group participants are provided in detail in Figure 13. Illustrative comments of the top common themes discussed in Figure 13 are provided below.



Few or No Child Care Options (103 comments):

There are not enough options for childcare for children and families of children with disabilities. *There is not a lot of support for families with children with special needs.* There are also *no childcare centers that accept children with special needs.* One commented that the lack of childcare means that *we have no social life because one of us has to be there [for child].* Other parents have had to adjust their schedules in different ways to ensure care for their child. *We adjusted our schedules to enable us to get a provider. It is sad when you can't work because you can't find childcare.* Another family member stated that *you can't do anything last minute because there is no respite care.*

Lack of Providers with Specialized Skills (41 comments):

Focus group participants stated that there are not enough providers of childcare with the skills and knowledge to care for children with disabilities. As one participant stated *there is no childcare available for the disabled children, as they don't know how to deal with the disabilities.* Family members provided examples of this, *the daycare in Tarkio had an autistic child, and they sat the child in the corner and ignored him because they didn't know how to deal with autism.* Family members agreed that *training needs to be provided to licensed day care*

providers so they can feel more comfortable and be more willing to take children with special needs.

Systems Requirements Limit Childcare Services (32 comments):

There are often system requirements that limit the types of childcare services a family may receive. One such system challenge is the fact that some childcare services have age caps. An example was provided by a focus group participant. *An organization provided all but two months of the year, and the age group had a cap, so we had to look for childcare when my son turned 13.* Another participant agreed. *When children reach age 12, they can't go to regular childcare. Providers can apply for a waiver but there are no incentives for the provider.*

Lack of Family and Friends to Provide Childcare (30 comments):

Focus group participants often lack childcare supports from family and friends. According to one participant, *it is difficult for families who don't have family or friends close who can help with childcare.* Others commented that using family or friends is not always appropriate, *I have my mom and my mother-in-law, but she [family member] exhausts them quickly. We can't do it for long. I go to school and work, and it is hard. I don't know what to do the next week.*

Excessive Costs for Childcare (20 comments):

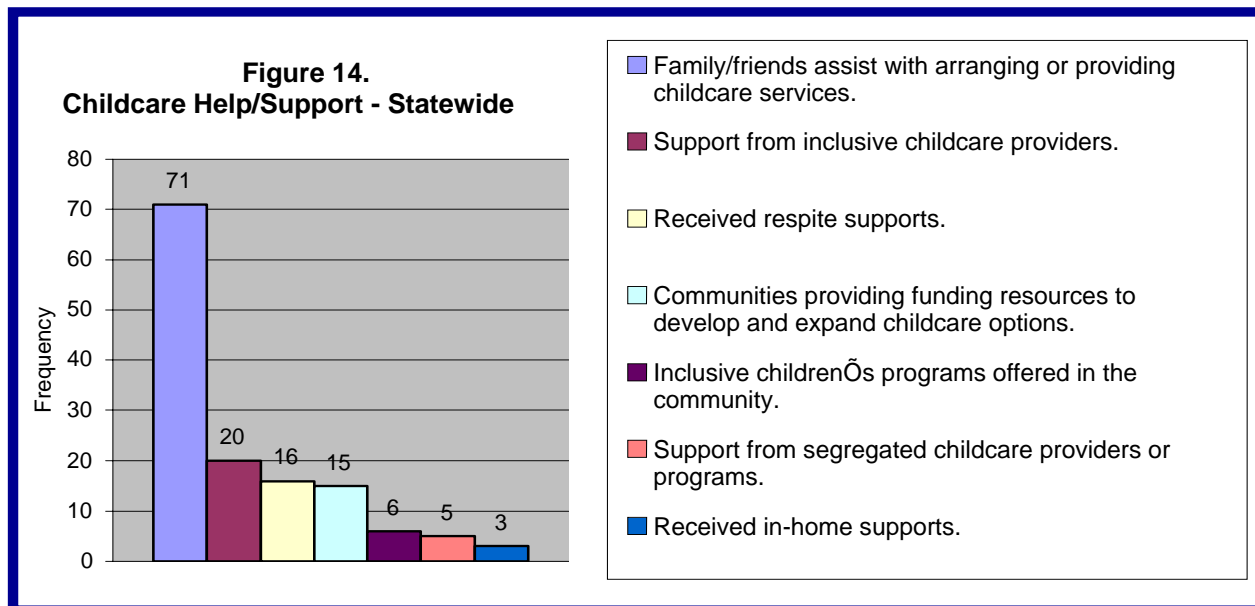
Childcare costs too much for many families to utilize the services. Families are forced to *pay for it out of pocket*, because there is no funding to assist them. One focus group member commented that *most of the people who need it [childcare] cannot afford it. Even if it is not too much, it is more than a lot of people can handle.*

Reductions in Funding/Services for Childcare (19 comments):

Childcare funding and services for children with disabilities have been reduced or cut in many regions. In one community, *Head Start had daycare, but it just got cut because of low enrollment.* Respite care is especially needed. One focus group member commented that they *were told there is no respite care in this area because of funding.* Another commented that *respite at one time was wide open. Now it has shifted back to the state. It is only \$500 a year. Respite is an area that needs attention.*

Childcare Help and Support:

Focus group participants also discussed the types of help and support they receive for childcare. One common theme as stated by the participants was help and support from family and friends in assisting, arranging, or providing childcare services (71 comments). Common themes from the focus groups are presented in detail in Figure 14. Illustrative comments of the top common themes are also provided in detail below.



Family and Friends Assist with Childcare (71 comments):

According to focus group participants, many rely on *family or friends* to provide supports. Some examples include:

- *Osage County family and friends program pays a family friend to watch your child.*
- *We use family members for childcare. Some of my friends are working on degrees to get a daycare started.*
- *Grandparents will baby sit.*
- *Both of my daughters are willing to baby sit if I am gone.*

Support from Inclusive Childcare Providers (20 comments):

Supports from childcare providers that are inclusive of children with disabilities are also utilized by families. Childcare provider supports included *quite a few churches in Hannibal* according to one focus group participant. Another participant stated that *Latchkey program at the YMCA was an option*. The *Boys and Girls Club* was also listed.

Communities Provide Funding Resources (16 comments):

Several focus group participants commented on the SOAR program available in schools for childcare. One participant stated that they *loved the SOAR program*. Another said they found *childcare options at their local hospital. The choices for families are quite good due to the Children's Center at the hospital which provides a nurse on staff.*

EARLY INTERVENTION SERVICE ISSUES

The next section of the survey examined issues related to early intervention programs or services. The programs that the survey focused on were: (1) First Steps; (2) special needs pre-school; (3) Head Start; (4) regular pre-school; and (5) therapies. *First Steps* was indicated as the

most likely to be used by 41.8% of the survey respondents. Regular pre-school was identified as least likely to be used by 30.2% of the respondents.

Table 11. Most and Least Likely Early Intervention Service Choices

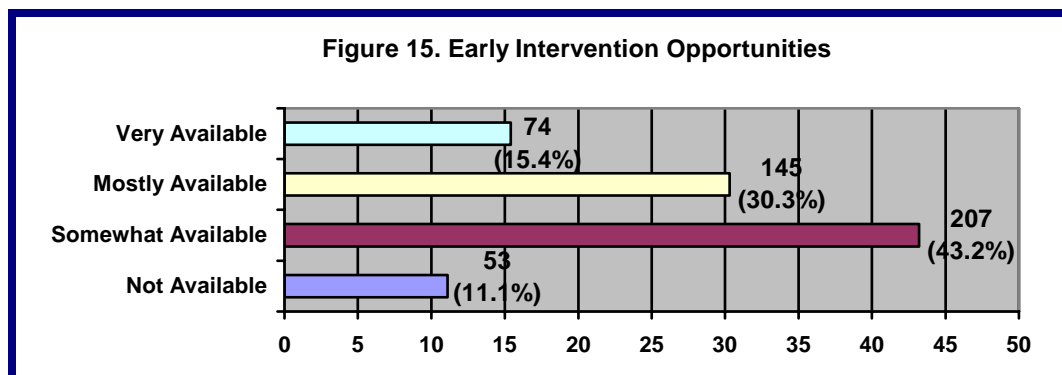
Item	First Steps	Special needs pre-school	Head Start	Regular pre-school	Therapies
Child services	185 (41.8%)	50 (11.3%)	114 (25.7%)	31 (7.0%)	63 (14.2%)
Child services least likely	60 (14.3%)	105 (24.9%)	59 (14.0%)	127 (30.2%)	70 (16.6%)

The adequacy of early intervention services was rated on a four-point scale (1=Inadequate...4=Excellent). Both First Steps and Head Start received the highest means (2.71 and 2.69 respectively). Table 12 presents the data.

Table 12. Adequacy of Early Intervention Services

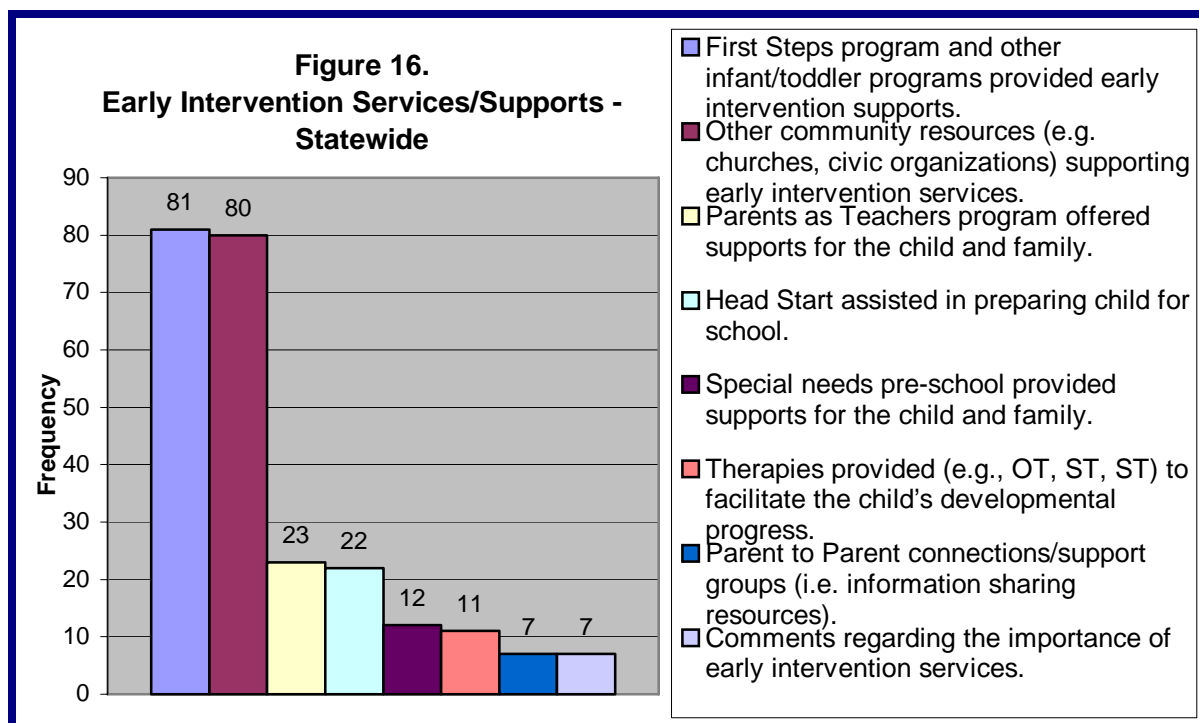
Item	Inadequate	Fair	Good	Excellent	Mean
First steps/infant-toddler programs (454)*	77 (17.0%)	100 (22.0%)	156 (34.4%)	121 (26.7%)	2.71
Special needs pre-school (430)*	146 (34.0%)	89 (20.7%)	130 (30.2%)	65 (15.1%)	2.27
Head Start (423)*	45 (10.6%)	129 (30.5%)	163 (38.5%)	86 (20.3%)	2.69
Regular pre-school other than Head Start (410)*	117 (28.5%)	130 (31.7%)	114 (27.8%)	49 (12.0%)	2.23
Therapies (436)*	105 (24.1%)	113 (25.9%)	142 (32.6%)	76 (17.4%)	2.43
Scale: 1=Inadequate...4=Excellent *Total number responding					

Figure 15 shows how respondents rated the availability of early intervention services in their community. The rating was on a four-point scale (1=Not Available...4= Very Available). Approximately 74% of the respondents saw early intervention services as *mostly available* or *somewhat available*.



Early Intervention Services and Supports Focus Group Questions

Focus group participants discussed the types of early intervention services they had received for their family member with disabilities. A majority of individuals commented on the First Steps program in their communities (81 comments). The major themes from the focus group are presented in Figure 16. Illustrative comments of the top major themes are also provided below.



First Steps and Other Infant Programs (81 comments):

Several comments were made about the First Steps program, as well as other infant and toddler programs as providers of early intervention. One participant stated that the *First Steps* program was *phenomenal*. A parent stated that *First Steps is a great program. Early therapies make a huge difference in how far a developmentally disabled child can go in developing to their full potential*. There is some concern that the First Steps program might be eliminated because *if they take First Steps away we will have a lot of kids with problems not getting help*.

Other community resources (e.g. churches, civic organizations) supporting early intervention services (80 comments):

Focus group participants received help from community resources such as civic organizations, schools, and charity groups for help with early intervention. One participant *found a group in Kansas City and it had pretty good results. The company was had to pay for it ourselves. But we did have good luck*. Other comments about help from different resources for early intervention are included in detail below.

Offers of Help and Assistance: Important for some of the focus group participants were simply the offers of help and assistance they received from community resources. One focus group participant was grateful because *I feel that we were not made to feel that we were begging for help. It was there for us when we needed it. I met people in town that would help me out and tell me who to call. People in the community were great.* Another added *my son had all kinds of offers for services. We had a caseworker that linked us to everyone that could help.*

United Cerebral Palsy Provided Assistance: Several focus group participants discussed the assistance with early intervention they received from United Cerebral Palsy (UCP). One participant provided the example *I had two children that were enrolled in the United Cerebral Palsy program and the Albany Regional Center. I now realize that each child is different.* Other focus group participants had similar experiences *we went to United Cerebral Palsy. We got directions to go that way, we felt like the services were there if they needed it. The Lady at United Cerebral Palsy did some amazing things and the lady there got her [family member] to do things.*

Regional Center Provided Assistance: Regional centers throughout the state of Missouri were another resource for early intervention and assistance. One focus group participant provided an example of the assistance received from their regional center. *In 1st grade, my son was diagnosed and then we took him to the Albany Regional Center. I think a lot of my son's caseworker.* Another focus group participant added *I went through the Albany Regional Center and within a week our child was in United Cerebral Palsy (UCP) in St. Joseph.*

Early Childhood Programs in the Community: Several focus group participants and their family members have received early intervention assistance from schools and pre-schools. One participant in a focus group gave an example of a school program in their area *there is an early childhood program, Community Opportunities provides a pre-school. It is very organized and very structured and meets the needs of the consumers.* Another focus group participant stated that the public schools provide early intervention. *There is an early childhood program in the Rolla schools.*

Some private schools in communities provide better services for children with disabilities. Some even provide free school services *Ursuline Academy in Crystal City allows some children with disabilities to attend.* Another example of a private school providing services was *Good Shepherd School in the St. Louis area was a very good program. Our son was progressing well until he left there and attended a public school.*

Parents As Teachers Program Offers Support (23 comments):

Parents As Teachers is another resource for early intervention. It has helped a number of families. One focus group participant gave the example that they had used *Parents as Teachers and they were the first people to actually notice there were some problems.* Other participants

had had similar experiences with the *Parents as Teachers Program*. They can usually detect if the child is not at the level they should be and can refer you to places to receive help.

Head Start Program (22 comments):

Focus group participants felt *the Head Start program was a wonderful experience*. This program is especially important in small communities where there may not be other programs for early intervention. One focus group participant stated that *the Head Start was available and was very supportive in the early intervention process in our small community*.

Other Comments:

Other comments that are illustrative of early intervention for people with disabilities include:

- *Train volunteers to be parent mentors that would be volunteer or cheaper. Could get more people off of waiting list.*
- *Need more early intervention services, especially in rural areas.*
- *More training for medical and social service professionals on DD and early intervention.*

EDUCATIONAL SERVICE ISSUES

The survey respondents were asked what type of school services were most and least likely to be used. The types of educational services were: (1) included in regular public school education; (2) special public school education; (3) state school education; and (4) private home education. Few used private/home education (5.6%). Respondents indicated that the most often used educational services were either special public school education (46.1%), or included in regular public school education (33.7%). (See Table 13.)

Table 13. Most and Least Likely Educational Services Choices

Item	Included in regular public school education	Special public school education	State school education	Private/home education
What types of educational programs most likely to use	163 (33.7%)	223 (46.1%)	71 (14.1)	27 (5.6)
What types of educational programs least likely to use	108 (23.9%)	35 (7.7%)	119 (26.3%)	190 (42.0%)

The adequacy of educational services was rated on a four-point scale (1=Inadequate... 4=Excellent). The highest rated educational type was *special public school education* (mean of 2.51). The lowest was *private-home education* (mean of 2.12). Table 14 presents the findings.

Table 14. Adequacy of School Services

Item	Inadequate	Fair	Good	Excellent	Mean
Included in regular public school education (557)*	123 (22.1%)	191 (34.3%)	176 (31.6%)	67 (12.0%)	2.34
Special public school education (532)*	99 (18.6%)	149 (28.0%)	200 (37.6%)	84 (15.8%)	2.51
State school (387)*	115 (29.7%)	85 (22.0%)	123 (31.8%)	64 (16.5%)	2.35
Private-home education (351)*	122 (34.8%)	106 (30.2%)	83 (23.6%)	40 (11.4%)	2.12
Scale: 1=Inadequate...4=Excellent *Total number responding					

Respondents were asked to rate the availability of (1) inclusive educational opportunities; (2) transition services; and (3) post-high school opportunities in their community. Figures 17-19 detail the results.

Figure 17 shows how respondents rated the availability of inclusive educational services in their community. The rating was on a four-point scale (1=Not Available...4= Very Available). *Inclusive educational opportunities* were seen as *somewhat available* by 49.2% of the respondents.

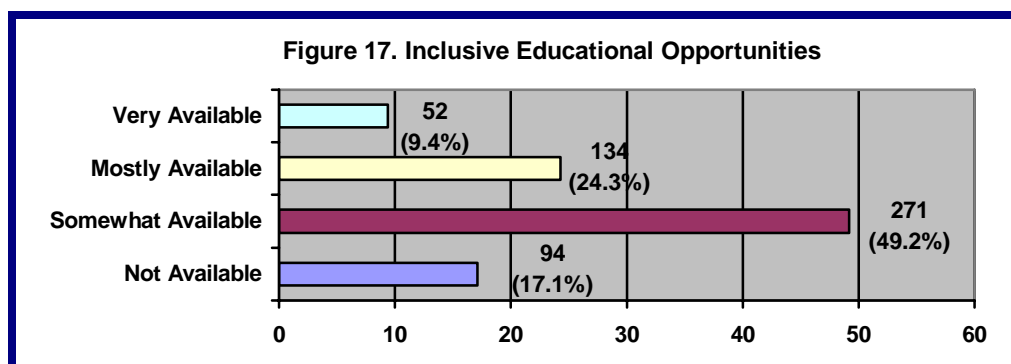


Figure 18 shows how respondents rated the availability of transition services for people with disabilities from school to work in their community. The rating was on a four-point scale (1=Not Available...4= Very Available). *Transition services* were seen as *somewhat available* by 48.4% of the respondents.

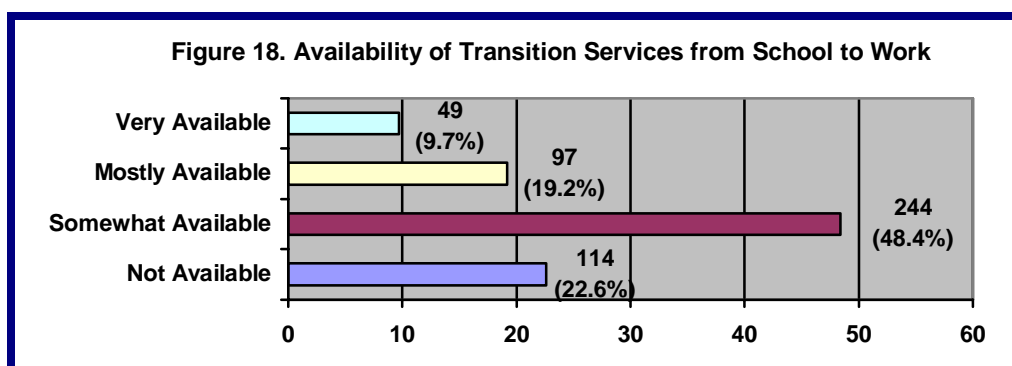
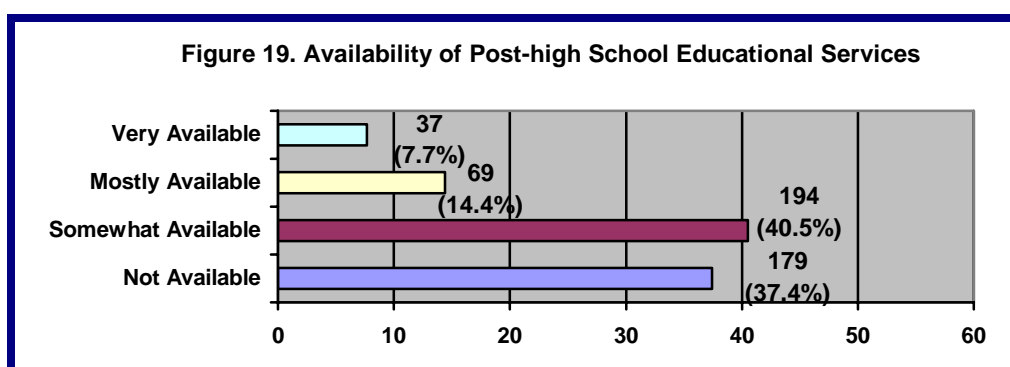


Figure 19 shows how respondents rated the availability of post-high school educational opportunities for people with disabilities in their community. The rating was on a four-point scale (1=Not Available...4= Very Available). The availability of post-high school educational opportunities was seen *somewhat available* (40.5%) or *not available* (37.4%) by almost 78% of the respondents.

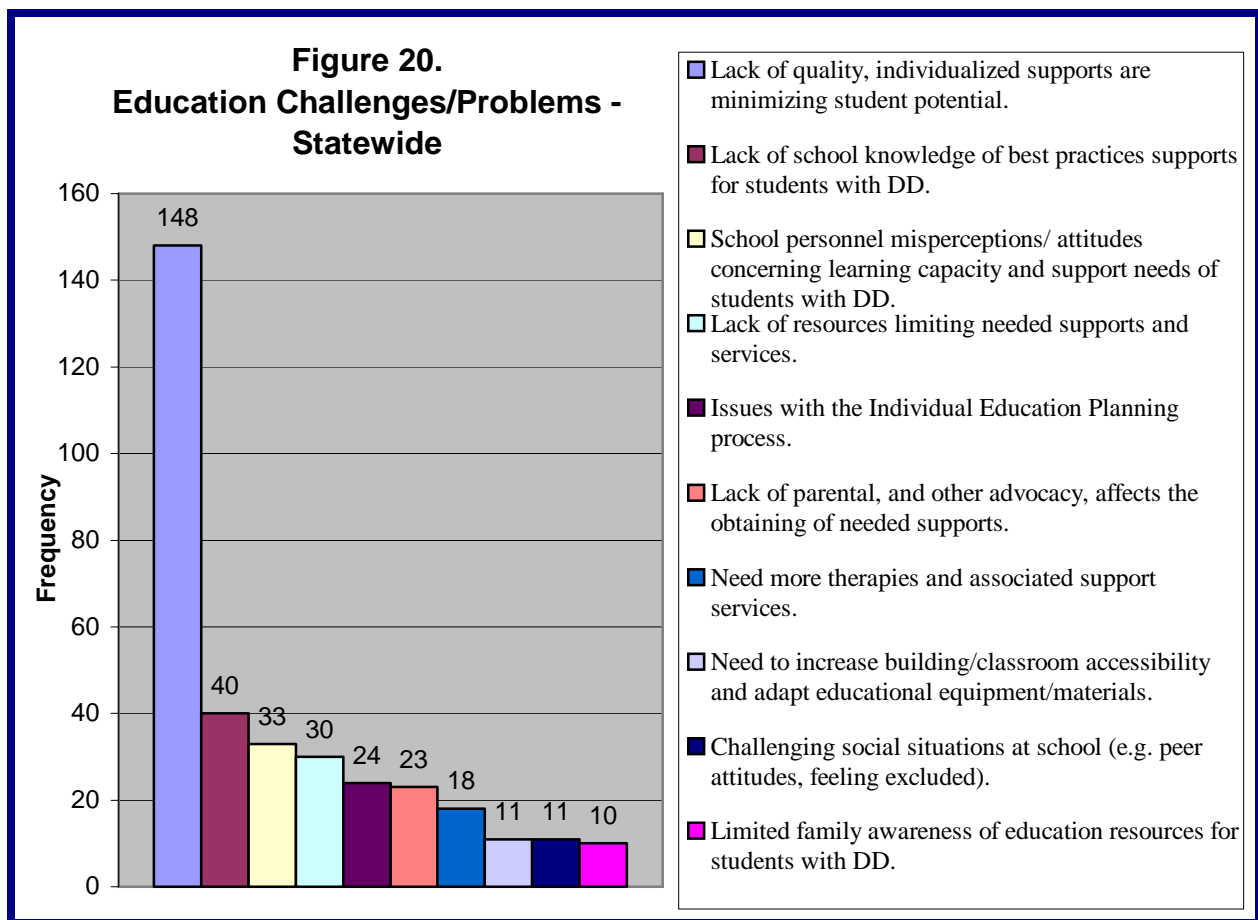


Education Focus Group Discussion

Focus group participants were asked to discuss the (1) Problems and challenges they have experienced with the education system and (2) Types of help and supports they have received with education. The focus group discussions on education issues are in detail in the section below.

Challenges and Problems in Education:

The focus group participants discussed the challenges and problems in receiving educational services and support. A common theme was the fact that the lack of quality, individualized supports is minimizing student potential (148 comments). Focus group themes are analyzed in detail in Figure 20. Illustrative comments from the top common themes about educational challenges and problems are also provided in detail below.



Lack of Quality Individualized Supports (148 comments):

Several focus group participants commented on their frustration with the lack of supports needed for their family members or themselves to receive a good education. In some instances, family members *don't know if schools are listening*. In one instance, education professionals such as *teachers and administrators lack the education about specific disabilities and are not receptive to training or packet information* that was furnished by a family. Other comments about the lack of quality supports are included in detail below.

No Service or Support Availability: Comments were made about the complete lack of services. When some individuals attended school, *there were no services*. Other participants echoed this *we have no providers no Parents As Teachers, no help. The school thinks that it doesn't have to provide any of these services*. Other participants made related comments *no support is available from school in classrooms. No aide, no assistive technology, no independent providers of therapy, no individualized supports*. Another problem is that the school will not pay for services or equipment. One parent provided the example *the Mayo Clinic diagnosis says he [my child] needs certain things, the school says they aren't going to pay for it*. Others stated that *we have a lot of deaf kids not receiving the proper interpreters*.

Classrooms Are Segregated: Public schools do not do enough to incorporate children with disabilities into the classroom with other children. One parent expressed frustration at this practice *my son has been segregated in a room by himself with teacher aides. He is not even in special education. They have had no plan to get him back into the classroom.* Another parent echoed this frustration. *My daughter sits by herself because that is what the school says needs to be done.* Another experience was discussed by a family member *I received good support up to middle school. Once in high school, it was uncooperative and did not want her in inclusive classrooms.*

Schools and Teachers Don't Want to Take the Time: There is the perception that schools and teachers do not have time to deal with children with disabilities. One participant in the focus group stated that they have heard *teachers say that the state has put too much on them and they don't have time to deal with a child with disabilities.* Others say some supports are available but educational professionals don't have time. *The school has some programs but the teachers do not want to deal with some of the kids.* Another focus group participant provided a personal experience with this. *I needed help. Math was hard. The teachers were busy with other kids and put me on the back burner.*

Education is not Individualized: Children with disabilities deserve to receive education that is individualized to meet their needs. Several comments were made about the lack of individualized educational supports. One parent stated that *education which is truly individualized is very elusive.* Another parent stated that they think their *daughter needs an aide in the mornings* in order to succeed. Another focus group participant stated that *special education needs to be more individualized.*

Transitioning Assistance: There is a lack of assistance in transitioning out of school. One person commented that *there were always problems, including transitioning from the system which was inadequate.* Another person stated that schools *should prepare and transition a person with a disability to life and work after high school* as part of their educational support. Another stated that *more job training and transition planning is needed.*

Lack of School Knowledge of Best Practices (40 comments):

Schools and educational professionals lack the knowledge of best practices for students with developmental disabilities. Some *teachers say they don't know how to adapt the class* for students with developmental disabilities. One reason for this might be because *Paraprofessionals lack training to be able to deal with everything.* According to another focus group participant *teachers are not trained to deal with children who have developmental disabilities.* Other focus groups participants agreed with this statement, *regular education teachers are not trained for inclusion.*

School Perceptions about Learning Capacity and Support Needs (33 comments):

Focus group participants commented that there is a problem with the school perceptions of learning capacity and the support needs of children with developmental disabilities. *Perceptions of teachers can cause problems in education* as one focus group participant stated. Another participant in the focus groups stated that *a lot of it is the attitude of the schools. If they are accepted or not, it just depends on the school. We need to give our classroom teachers a little more help.* Nonetheless, *system problems and the lack of understanding are pervasive.* One example given by a focus group participant was *the teachers knew my son. They knew if he came to their class, he was going to be a problem. That was a preconceived notion.*

Lack of Resources (30 comments):

The lack of resources limits the needed educational supports that children with developmental disabilities are able to utilize. One example given by a focus group participant is that *there is a vocational school [for my family member] but it is hard to get there because of accessible transportation.* Another person expressed frustration because their child *doesn't get to go to other classes because there is no money to hire someone to go with my daughter.* Some regions are deeply affected by the lack of resources. *There is a lack of funding in rural areas for individuals with disabilities.* There is a *need for more grants to be set aside for education and adaptations for higher education.*

Issues about the Individualized Learning Process (24 comments):

In some regions, *it is a battle to get Individualized Educational Plans (IEP) to work* for children with disabilities. Focus group participants commented that *teachers don't read the IEP's.* Another added that *the teachers don't come to the IEP meetings.* Another problem according to participants is that *professionals don't know the IEP process. If a caseworker attends an IEP, they don't often know the process and when they are not trained, it does no good.* Parents feel they are not being included in the planning and that *the IEP's are being filled out prior to meeting and parent input.*

Lack of Advocacy Effects Obtaining of Supports (23 comments):

Focus group participants discussed the lack of parental and other types of advocacy on obtaining the needed educational supports for children with developmental disabilities. Some focus group members gave examples. *While we maintained a pleasant relationship with the local school system, each year was a struggle to receive appropriate services.* Another participant added that *there is no community support, I am always advocating like a bully when I went to Individualized Educational Planning (IEP) meetings.* This was a common sentiment among participants. Another stated that *even with minimal special needs, the parents don't know who to call. I have to make people sick of me just to get my child services.*

More Therapies and Associated Support Services Are Needed (18 comments):

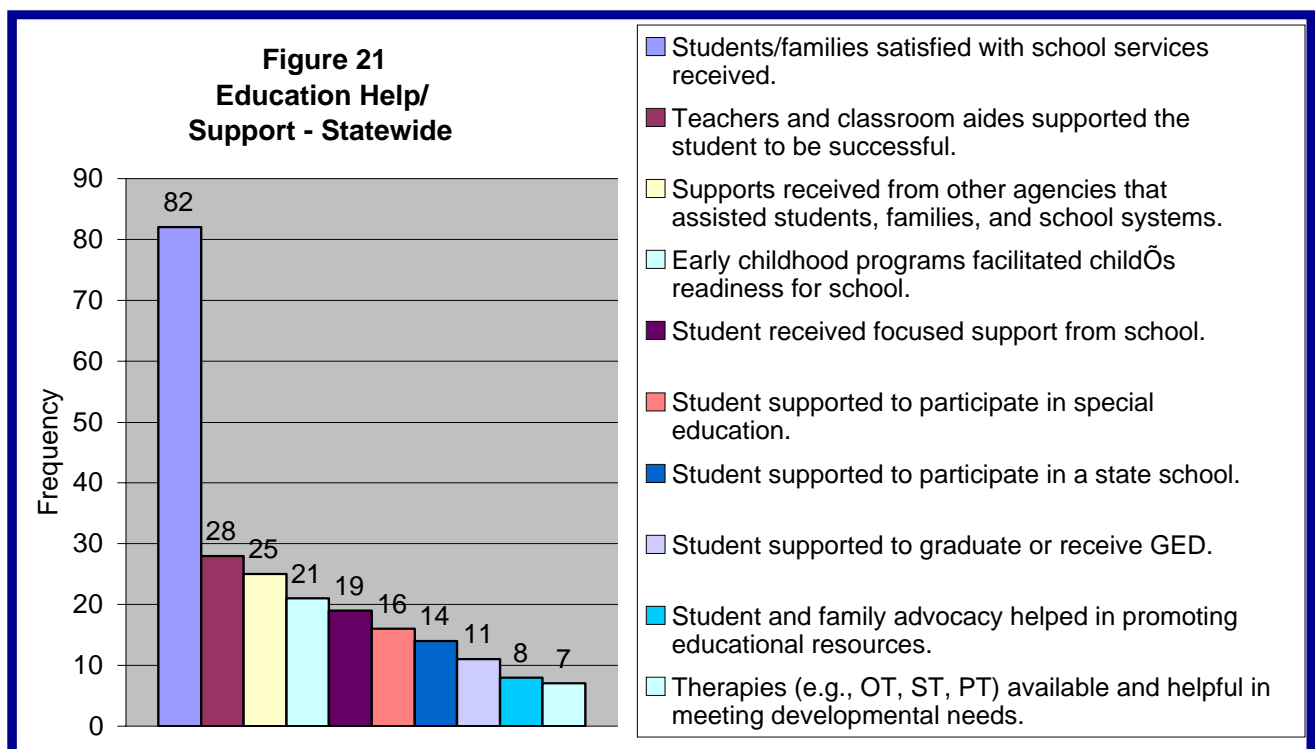
More therapy and associated support services are needed for children with developmental disabilities. One focus group participant gave the example that their *daughter needs occupational therapy and can only see an occupational therapist through the school about once a month*. Another participant has access to no therapies. *No therapy is being provided by the school. They just do not have anyone on staff, so my family travels to another county*. Receiving therapies throughout the year is also an issue, *summer school was a problem because the communication system was different, and therapies had not been assigned. My family member ended up getting nothing all summer*.

Other Comments:

Other comments included that *there is a need for consistency with all the school programs to look at the long run and graduation. We need to be able to have diversity in society*.

Educational Helps and Supports:

Focus group participants also discussed the types of educational helps and supports they received that helped maximize educational potential. A common theme among the participants was satisfaction with the school services that had been received (82 comments). Common themes are presented in Figure 21. Illustrative comments related to the top common educational supports themes are also provided in the section below.



Students and Families are Satisfied (82 comments):

Many comments were made about the satisfaction with the level of educational supports and services received. One focus group participant stated *this county's school has been receptive and positive and open to ideas. We are very pleased.* One focus group participant gave an example *we are going to school. We did First Steps. Now we are doing Early Childhood Education. We had an Individualized Education Plan (IEP) statement in paper, we 90% exceeded reading expectations.* Another participant stated *although we struggled at times, the school system was supportive of our needs.* One focus group participant gave a personal example, *my experience was good. I got special attention because I was the only one. I got everything I wanted.* Other related comments about satisfaction with educational supports and services are below.

- *My son is eight right now I am pleased with the system. We have a full time aide.*
- *My family member's transition from school to the workshop went smoothly.*
- *Transition from Junior High last year went well.*
- *The school system is better than it was ten years ago. Supports in schools, we feel, are better.*
- *Special school district for early childhood is great.*

Teachers and Classroom Aides Supported Students (28 comments):

Help and support was received by teachers and classroom aides. One focus group participant stated that *there were lots of positive things in the local school districts--excellent teachers that have been recognized for their accomplishments working with students with disabilities.* Another commented that *paraprofessionals in the classroom make a big difference.* A personal example of teacher and aide support was provided by a focus group participant, *he [family member] has an aide that works with him the whole time and that was a big bonus for him at first.* Another student got the support needed from teachers and *has turned from a D or F student to an A, B, C student.*

Supports Received from Other Agencies (25 comments):

Focus group participants listed some of the agencies and organizations that provided them with educational supports. A few listed the *ACED program. It is a well run program.* Another participant noted *family services have been very supportive for teachers and administration.* Other agencies that provided educational support are listed below.

- *BASE program at Springfield Regional Schools teaches you skills.*
- *Choices for People is very good at teaching safety in the community.*
- *The local college has a program entitled EXCESS and it is available to anyone who wants to further their education.*
- *The Parents Learning Together program is very important. It teaches parenting and literacy skills.*

Early Childhood Programs Facilitated Child’s Readiness (21 comments):

Early childhood programs have helped facilitate children’s readiness for school. One parent commented that *we like the early childhood program, and it has been great. We have been pleased with the integration of students and I see those being a network of friends for him later on.* Another parent stated that *early childhood did a good job of preparing my daughter for school. She is in “regular” class now.* One parent talked about the *Head Start program, it has a good ratio, so that if a child needs something extra, then the child receives it.* Several parents also commented that the *First Steps Program* was also an excellent program.

Student Received Focused Support from School (19 comments):

Receiving focused supports, such as tutors or aides was seen as helpful. One focus group participant commented that their *school hired an aide and got money from the state for expenses.* Another participant had *tutors come from the college* to provide support. One high school uses *A+ student’s to come down and help. When a peer helps, it is better than mom. It gives a feeling of normalcy.* Another focus group participant commented there were *good things, including continuum of services, a full-time aide is hired when needed, placed is where the child’s needs can be met.*

HEALTH CARE SERVICE ISSUES

Survey respondents were asked to identify where people with disabilities were most likely or least likely to go to get health care services in their community. Respondents were asked to select from the following types of health care services: (1) hospitals/emergency room; (2) doctor’s office; (3) community health clinics; (4) residential health center; and (5) local health departments. Over 62% of the respondents indicated that people with disabilities received their health care at the *doctor’s office* (62.2%). Few used *local health departments* (3.6%) or *residential health care centers* (3.6%). (See Table 15.)

Table 15. Most and Least Likely Health Care

Item	Hospitals/ emergency room	Doctor’s office	Community health clinics	Residential health care center	Local health departments
Where most likely to go for health care services	117 (22.2%)	327 (62.2%)	44 (8.4%)	19 (3.6%)	19 (3.6%)
Least likely to go	75 (15.0%)	29 (5.8%)	81 (16.2%)	208 (41.6%)	107 (21.4%)

The adequacy of health care services was assessed on a four-point scale (1=Inadequate... 4=Excellent). With the exception of *residential health care centers*, all other health care services were rated as *inadequate* or *fair* by over 50% of those who responded. *Hospitals/emergency rooms* were rated by almost 70% of the respondents as *inadequate* (30.0%), or *fair* (39.9%). *Doctor’s offices* were rated as *inadequate* (20.5%), or *fair* (46.7%) by over 67% of the respondents. Residential care center received the highest mean rating (2.70), and Hospitals/emergency rooms received the lowest mean rating (2.10).

Table 16. Adequacy and Availability of Health Care Services

Item	Inadequate	Fair	Good	Excellent	Mean
Hospitals/emergency room (596)*	179 (30.0%)	238 (39.9%)	119 (20.0%)	60 (10.1%)	2.10
Doctor's office (660)*	135 (20.5%)	308 (46.7%)	177 (26.8%)	40 (6.1%)	2.18
Community health clinics (562)*	139 (24.7%)	183 (32.6%)	70 (12.5%)	170 (30.2%)	2.48
Residential health care center (521)*	122 (23.4%)	133 (25.5%)	45 (8.6%)	221 (42.4%)	2.70
Local health department (579)*	130 (22.5%)	214 (37.0%)	75 (13.0%)	160 (27.6%)	2.46
Scale: 1=Inadequate...4=Excellent					*Total number responding

Figure 22 shows how respondents rated the availability of health care services for people with disabilities in their community. The rating was on a four-point scale (1=Not Available...4=Very Available). The availability of health care services was rated as *somewhat available* (34.9%), or *not available* (39.9%) by almost 75% of the respondents.

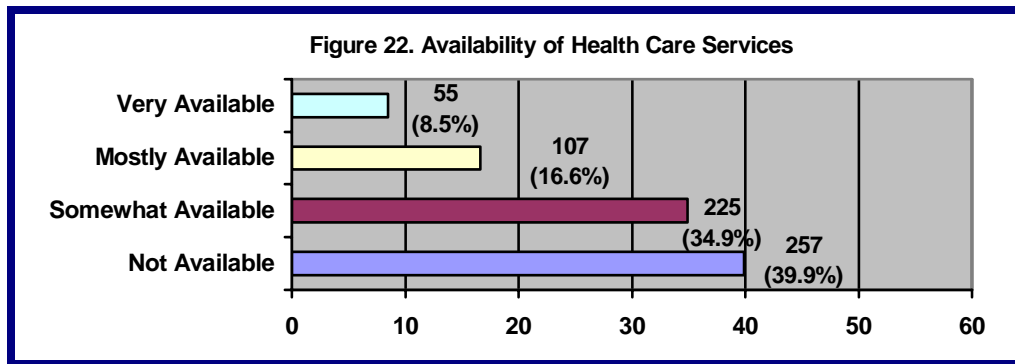
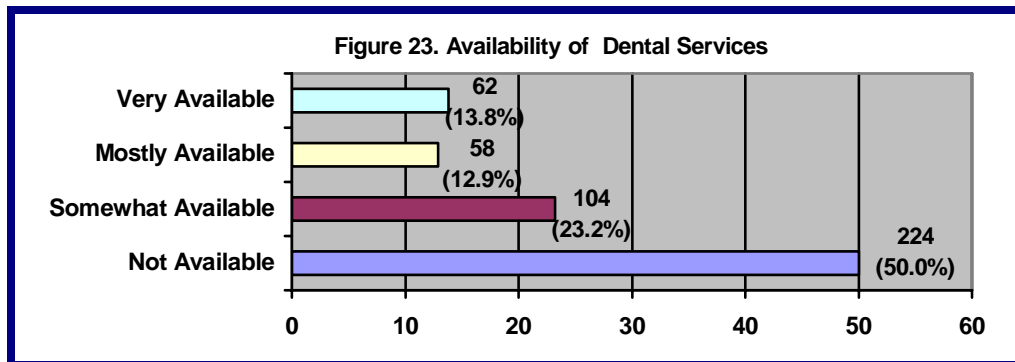


Figure 23 reflects how respondents rated the availability of dental services for people with disabilities in their community. The rating was on a four-point scale (1=Not Available...4=Very Available). The availability of dental services was rated as *somewhat available* (23.2%), or *not available* (50%) by over 73% of the respondents.

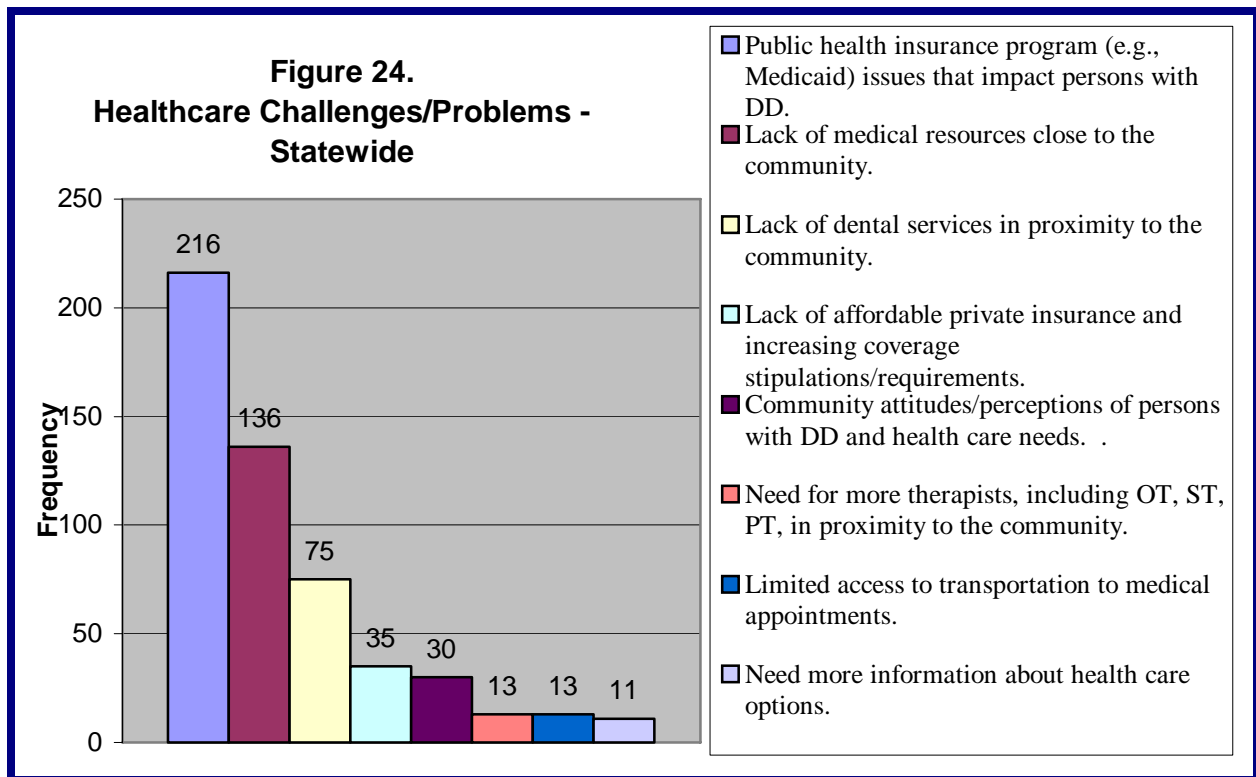


Healthcare Focus Group Discussion

Focus group participants from around the state were asked, “What kinds of problems/challenges and support have you or your family member faced in obtaining healthcare, or health related services?” This section covers the challenges and problems people have experienced as well as the help and support they have received.

Healthcare Problems and Challenges:

The top five problems and challenges in healthcare were public health insurance program issues that impact persons with DD (216 comments), lack of dental services in proximity to the community (134 comments), lack of general medical resources close to the community (76 comments), lack of affordable private insurance and increasing coverage stipulations/requirements (35 comments), and community attitudes/perceptions of persons with DD and healthcare needs (30 comments). Following are detailed comments along with Figure 24 showing the results of this topic.



Public health insurance program issues that impact persons with developmental disabilities (216 comments):

Many issues were covered under this topic. One person expressed, *my giant pet peeve... all our children's lives is that you want them to be independent... we have taken such extremely*

good care of them... then they turn 21 and then they don't qualify for things. This is just one concern out of many. Following are three areas of concern broken down into further detail.

Dental care: *There is a lack of dentists that will take Medicaid. Very few dentists in the area accept Medicaid. One parent felt that it is very difficult to find Dental Specialists to take Medicaid or even to take child with self pay. Other comments made were that dentists don't want to take people with disabilities and they will pay for dentures but not preventive services.*

Medicaid: *There were many comments made regarding issues around Medicaid including, I'm worried about the future of Medicaid, people with Medicaid are discriminated against, and budget cuts have left people without Medicaid. One parent explained, my daughter can't get Medicaid they say she does not have enough things wrong with her. Some people felt there was discrimination against Medicaid recipients and finding doctors to take Medicaid is a problem. One person shared, there comes a time when families have to make the decision to work and lose Medicaid and not work and have it if they do work how will they be able to pay for medicine and doctors?*

Wheelchairs: *The cost of wheelchairs and its upkeep is a big concern for many people. One person explained, what's coming up in our group is the wheelchair dilemma. They'll buy you a wheelchair, but they won't buy you batteries. Another person shared that We just got her a wheelchair under the wire... but the wheelchair has no warranty... it is hers... if it breaks.*

Lack of general medical resources close to the community (130 comments):

Problems pertaining to the lack of general medical resources varied. Obtaining health care in many of the smaller rural areas is an issue for many people. The services available might be overwhelmed because it is the only health care option for people in the area. *The doctors are overwhelmed with patients, it is hard to get in.* Another added *our doctors are overworked and understaffed. They are a family practice.* Other issues related to the lack of health care services are provided in detail below.

Must Travel Out of Area for Care: *Finding health care can be difficult in rural areas. Many must travel out of the area they live in to find proper health care. One focus group participant shared this: we have to go to Children's Mercy in Kansas City because the hospital here is not equipped to take care of pediatrics. Another participant stated I prefer to the city where the doctors are more educated.*

Time Spent Traveling for Health Care: *Travel time to see doctors was a problem for several people. A participant shared: We spend a lot of time driving to get to the doctors we need. Another participant added we take our child to St. Louis and it is an all day trip. Other focus group participants echoed this: We are required to travel 1 to 1 ½ hours to reach a doctor in Springfield or 2 hours to St. Louis.*

Travel and Transportation Costs a Barrier: While it is a necessity for many people to travel to larger cities or out of their area, transportation, and the costs incurred for travel are a barrier for several. Illustrative of this is: *We have to go to St. Louis for specialized care and transportation is a key issue for us.* Another focus group participant added that *going to a specialist in another town is expensive because of transportation.* Still another: *transportation to get health care is often a problem.*

Lack of Specialty Services: Finding specialty care is very difficult for many for a variety of reasons. Many people must travel out of their areas in order to find specialists. *The biggest barrier is finding doctors in any specialty. We go to doctors that take an approach to treat autism successfully. We have gone to all kinds of doctors. We went to Wisconsin for a good doctor. We are working with someone in Arkansas right now.*

Another focus group participant discussed the difficulty of finding specialists because of financial limitations. *Specialty care is really hard—to find someone that will take Medicaid. We don't find them often. Sometimes you will end up going to many different specialists before you get to the one you need to see.*

Lack of dental services in proximity to the community (75 comments):

The lack of dental services in proximity to the community has presented many problems and challenges for many people. Respondents shared; *there are no dental services and no dentists to work on persons with disabilities.* They also explained that *dentists don't take Medicaid.* Additional problems were found in the areas of Specialists and Finding Care. Following are these two topics broken down into detail.

Specialists: People found that it is *really difficult to see a specialist.* One person shared, *specialty care is really hard --- to find someone that will take Medicaid, we don't find them often – sometimes you will end up going to many different specialists before you get to the one you really need to see.* A lot of people have to travel to other towns in order to see a specialist. *If they need to be specialized, we must go out of our area to receive services.* People also found it difficult to find specialists. *For some specialties you cannot find doctors even if you do have insurance.* Another found that *good specialists are hard to find.*

Finding dental care: Many people felt that simply finding dental care was a big problem. Some comments made were: *Can't find dental care; can't find dentist who wants to touch a child; hard to get dental care, and waiting lists for a dentist of 6 months-1 year.*

Lack of affordable private insurance and increasing coverage stipulations/requirements (35 comments):

Many participants expressed concern about being able to afford healthcare, *healthcare is more strict each year. Standards of healthcare are stringent.* Comments varied from *can't afford insurance for family to co-pays and deductibles are too high.* People also found that *getting insurance is a huge problem and there is no aide for people who are even a little over the*

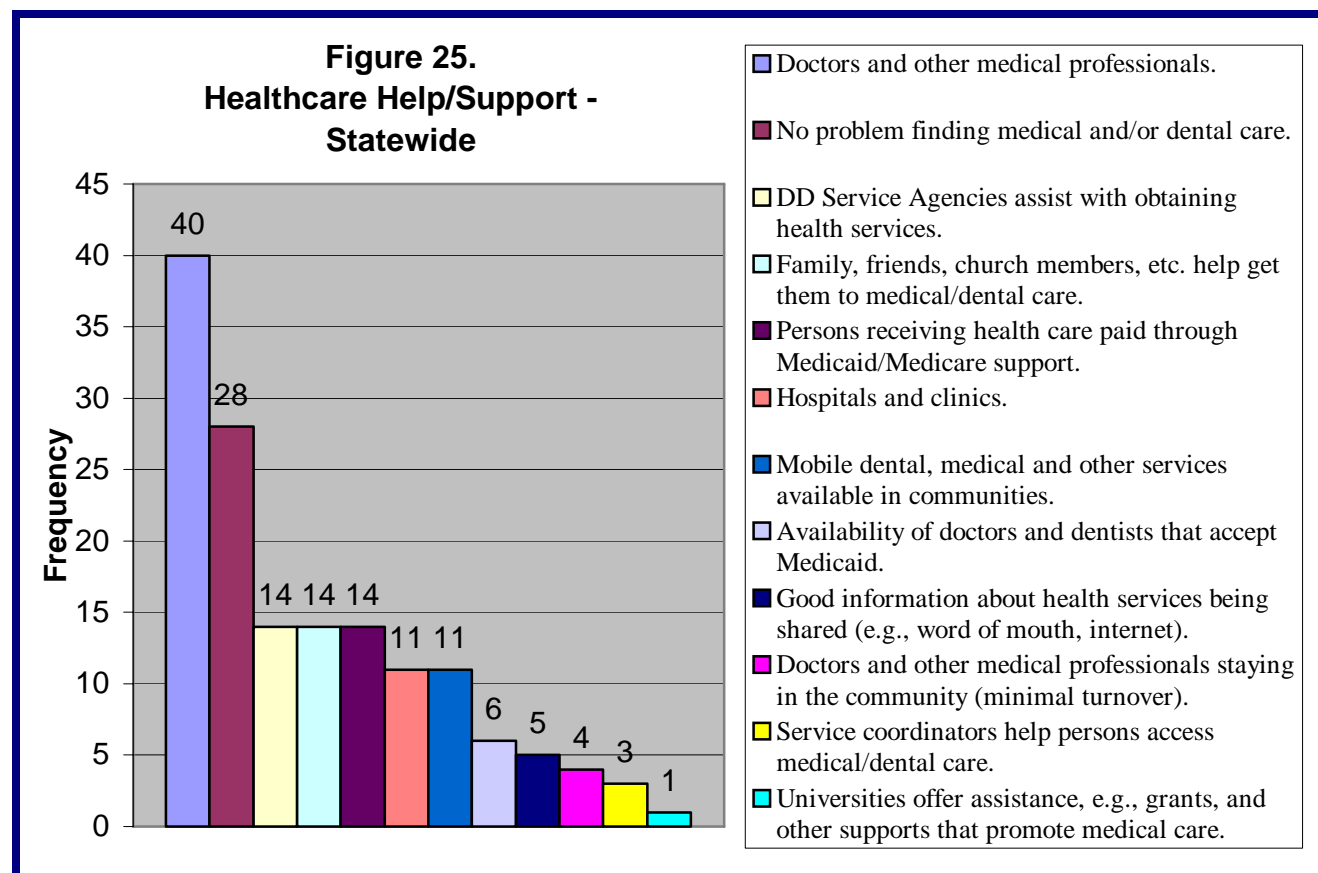
income limit. One woman said her husband went active duty in military so they could have good insurance. Another person added that their employer discontinued group health plan because of increase in premiums when employee had child with Down Syndrome.

Community attitudes/perceptions of persons with DD and healthcare needs (30 comments):

Focus group participants shared that they often times felt uncomfortable and uncared for. One person was *treated badly at hospital* while another felt the *nurse treats her like she is an idiot*. Doctors and hospital staff being uneducated about disabilities was another area of concern. Some of the comments people shared were: *Local physicians not reliable on a long term basis – not educated about special needs; hospitals and staff are not equipped or trained to treat persons with developmental disabilities; and sometimes staff not very helpful or knowledgeable about how to treat a patient with a disability.*

Healthcare Help/Support:

Focus group participants discussed the types of supports they had received with healthcare. Most people stated that they received help/support from Doctors and other medical professionals (40 comments) and that they had no problem finding medical and/or dental care (28 comments). Themes related to healthcare help and supports are included in Figure 25, as well as detailed comments relating to this topic.



Doctors and other medical professionals (40 comments):

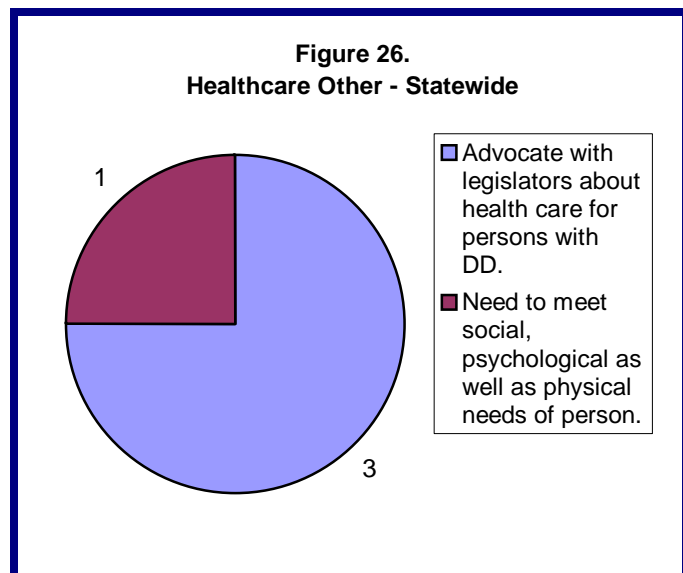
Many of the focus group participants stated that they found doctors and other medical professionals to be very helpful and supportive. Some parents found their pediatrician to be helpful: *We were fortunate when our son was small in that he was covered by medical insurance from my employer and that we had a very understanding pediatrician; and he continues to have a pediatrician that is able to work with him even after he turned 21 – he is great.* Some general comments about doctors were that: *my daughter’s doctor is very good and very thorough; doctor’s attitudes have improved over the years; doctor lets you make payments; and local doctor good with persons with disabilities.* People also had positive things to say about their dentist: *We go to Family Dental Health and only pay 10% of the bill and \$3 copay; local dentist is wonderful, and good dentist but doesn’t take Medicaid (he doesn’t charge much though).*

No problem finding medical or dental care (28 comments):

The people who responded to this topic felt that they had *no problem* in finding medical or dental care. One person had *no problem with the healthcare because of the military* while another had *no problem because she has Medicare and Medicaid – Dad is a veteran with a disability so that is how they get Medicare.* Some people *go to local clinic* while others are *cared for by a local doctor.*

Healthcare Other:

Focus group participants had the opportunity to discuss additional healthcare topics. The two topics of concern were *Advocate with legislators about healthcare for persons with DD* (3 comments) and the *Need to meet social, psychological as well as physical needs of person* (1 comment). One person shared that *we need to be a group of citizens and take control of congress. Combine groups and speak as a whole.* One person felt that *when I talk to legislators they listen.* Another person shared that *physical, psychological and social needs are not met in this area.*



RECREATIONAL/SOCIAL OPPORTUNITY ISSUES

The next part of the survey was related to recreational and social opportunities for people with disabilities in their community. There were three types of opportunities that were addressed: (1) regular community sponsored recreation and social activities/events; (2) accessible community sponsored recreation and social activities/events; and (3)

special/segregated recreation and social activities/events. Almost half of the respondents identified *special/segregated recreation and social activities/events* (49.8%), as being the most likely to be used, while another 34.7% identified *regular community sponsored recreation and social activities* as the type most often used . The *least likely to be used* was *accessible community sponsored recreation and social activity* (21.9%). (See Table 17.)

Table 17. Most and Least Likely Recreational/Social Opportunities

Item	Regular community sponsored recreation and social activities	Accessible community sponsored recreation and social activity	Special/segregated recreation and social activities/events
What types of social activities most likely to use	159 (34.7%)	71 (15.5%)	228 (49.8%)
What types of social activities least likely to use	208 (47.1%)	97 (21.9%)	137 (31.0%)

The adequacy of the types of recreational and social opportunities was rated on a four-point scale (1=Inadequate ... 4=Excellent). Of those rating *regular community sponsored* opportunities, almost 72% rated the opportunities as *fair* (28.4%), or *inadequate* (43.5%). *Accessible community sponsored opportunities* was rated as *fair* (30.3%) or *inadequate*(39.7%) by 70% of those who responded to the question. Over 41% of those responding rated *special segregated* opportunities as *good* or *excellent*. It also received the highest mean (2.20) of the three choices. (See Table 18.)

Table 18. Adequacy of Recreational/Social Opportunities

Item	Inadequate	Fair	Good	Excellent	Mean
Regular community sponsored (573)*	249 (43.5%)	163 (28.4%)	118 (20.6%)	43 (7.5%)	1.92
Accessible community sponsored (547)*	217 (39.7%)	166 (30.3%)	121 (22.1%)	43 (7.9%)	1.98
Special/segregated (505)*	187 (35.0%)	131 (24.5%)	141 (26.4%)	76 (14.2%)	2.20
Scale: 1=Inadequate...4=Excellent *Total number responding					

Figure 27 shows how respondents rated the availability of accessible recreation opportunities for people with disabilities in their community. The rating was on a four-point scale (1=Not Available...4= Very Available). Availability of accessible recreation opportunities in the community was rated as *somewhat available* (43.3%), or *not available* (28.7%), by 72% of the respondents.

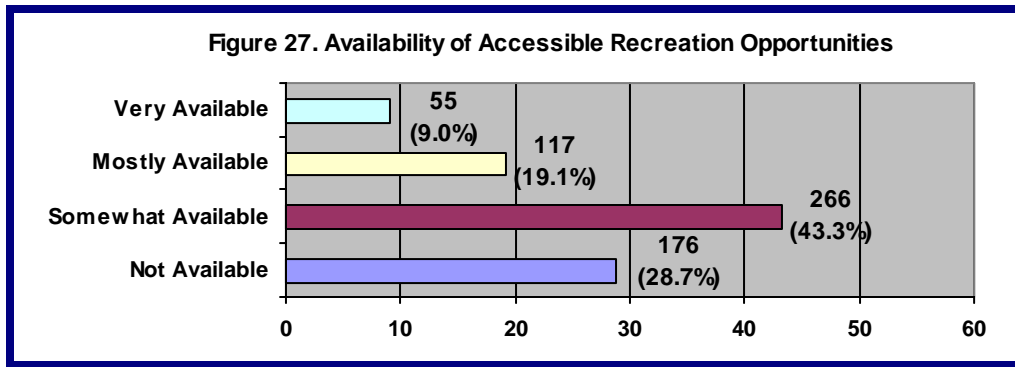
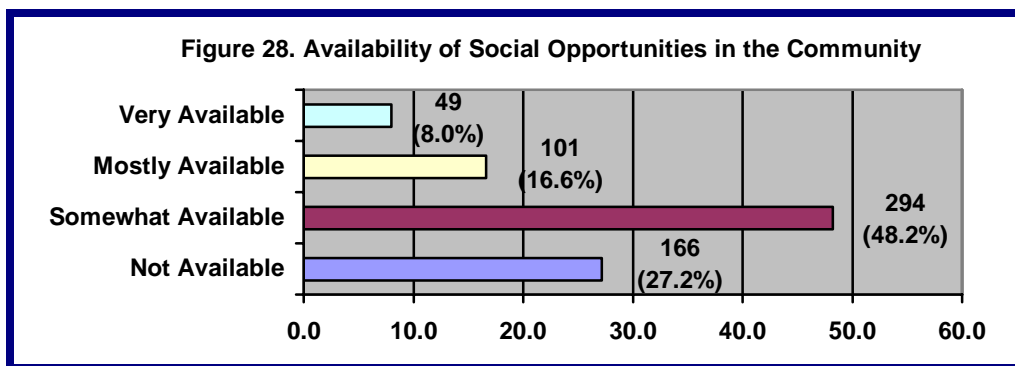


Figure 28 reflects how respondents rated the availability of social opportunities for people with disabilities in their community. The rating was on a four-point scale (1=Not Available...4= Very Available). Availability of social opportunities in the community was rated as *somewhat available* (48.2%), and *not available* (27.2%), by over 75% of the respondents.

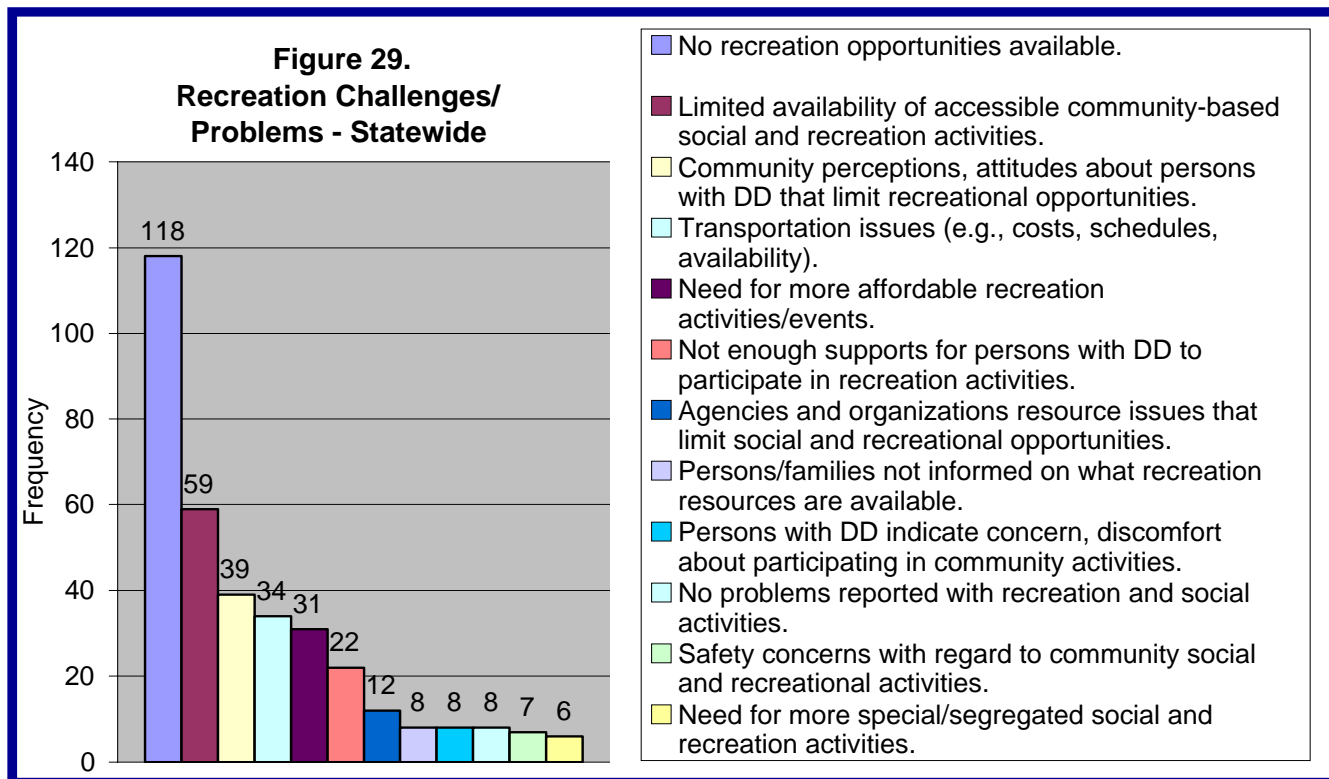


Recreation Focus Group Discussion

Focus group participants discussed the types of barriers and challenges they have experienced in trying to participate in social and recreational activities. The participants also discussed the types of supports and help they have received to participate in these activities. Issues related to participation in social and recreational activities are provided in detail in the section below.

Recreation Challenges and Problems:

The focus group participants discussed their experiences with challenges and problems participating in social and recreational activities. There were several comments that no recreation opportunities were available (118 comments). Common themes are provided in Figure 29. Illustrative comments relating to the most common themes are also provided below.



No Recreation Activities are Available (118 comments):

Community activities are not always available for individuals with disabilities. This is especially true in smaller rural communities. Sometimes as one participant stated, *if there is recreation, you have to go to another county*. Another related comment from a focus group participant was *there really is nothing in this county. You have to go outside*. Other comments relating to the lack of recreational activities are provided in detail below.

Activities are Segregated from Community: According to one focus group participant, *there is no inclusion* when it comes to recreational activities. Others agreed, stating that recreation activities were *not inclusive* and *too segregated*. Individuals with disabilities might have some recreational activities but they are *kept separate from others in the community*. The activities tend to *lump all disabled people together*.

No Programs for People with Disabilities: In many communities, there are no programs specifically for individuals with disabilities. One participant commented our *community is very limited as far as recreation for individuals and even more limited for individuals with disabilities*. We often have to drive to other towns to participate in recreational activities. One focus group participant stated that there was *nothing for adults with disabilities in Daviess County*. In another community there are *none that involve kids with disabilities*. *If they have outside activities I have to stay with them*.

Limited Availability of Activities (59 comments):

There is limited availability to accessible community-based social and recreational activities. Several focus group participants provided examples of the types of recreation and activities that are generally not accessible in their communities. In some communities *even the playground isn't accessible*. Another individual provided an example *you have a park, but it has too many hills, and you can't use a wheelchair on it. You can only go to church for fun*. Another participant stated that individuals *can't get around the playground. The ladders on the playground equipment are too high and the child cannot get on the equipment*. Other comments related to the lack of accessible activities are:

- *They are not wheelchair accessible.*
- *We need more variety of special activities and community activities that are accessible.*
- *We need a swimming pool. We have the river, but you can't take a person in a wheel chair in the river.*

Community Perceptions and Attitudes Limit Recreational Availability (37 comments):

Focus group participants had several comments about community perceptions of individuals with developmental disabilities that limit recreational opportunities. One participant stated that there was *not a lot offered* and there are *untrained volunteers that don't understand children with disabilities*. One parent had a son who did t-ball. *The next year, the coach didn't want my son on the team*. A parent talked about a personal experience with her child. *My child is not accepted in Girl Scouts. She has been going for years. She is just there. She does the activity, eats the snack and that is it. They don't call her. They don't invite her to birthday parties.*

Transportation Issues (34 comments):

Participants in the focus groups commented that there was a lack of transportation to and from recreational activities. One focus group participant stated *it is a problem to get transportation to get to recreation activities if you do not live in a group home*. Other participants echoed this sentiment. One stated that *I think a lot [of the issue] goes back to transportation. I am sure everyone would like to be more involved in fun things, but transportation is an issue.*

Need for More Affordable Recreation (31 comments):

Many recreational and social activities are cost prohibitive. *If there is recreation, it is very expensive*. Other focus group participants provided examples such as *there is nothing that we can afford. There are no local YMCA programs*. Another stated *we cannot afford to go to the movies*. Another example is the *Caruthersville Recreational Center. It is available for a per visit fee or if you buy a pass. Families can't afford this.*

Not Enough Supports to Participate in Recreation (22 comments):

Focus group participants stated that there are often not enough supports for people with developmental disabilities to participate in recreational activities. One parent *called about a soccer program. They didn't say yes or no to my son's needs. I just wasn't sure if they could*

accommodate him. Another parent stated *I would like for my son to do horseback riding, but I can't find any information on it.*

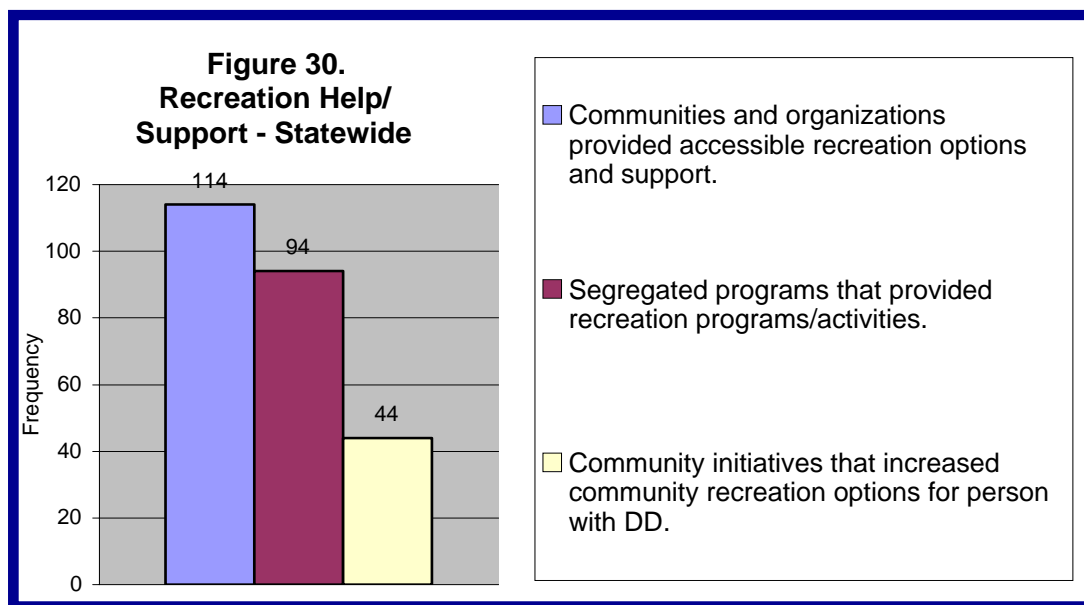
Other Comments about Problems Experienced with Recreation:

Some other illustrative comments about problems and challenges experienced while trying to participate in social and recreational activities include:

- *I can't find a babysitter for my three children. No one can handle all of them. No one wants to.*
- *Many Special Olympics Activities take place during the day when working parents cannot attend.*

Help and Supports for Recreation:

Focus group participants also discussed the helps and supports they have received in order that they and their families could take part in recreational and social activities. One common theme was the help from communities and organizations that provided accessible recreation options and support (114 comments). Commonly discussed themes about help and support for recreational activities are provided in detail in Figure 30. Illustrative comments about the most common themes are also provided below.



Communities and Organizations Provide Accessible Recreation (114 comments):

There are many different community organizations that have provided accessible recreation to people with disabilities including the *Boy Scouts*, *it is great*. The *Girl Scouts* also provide help. They *accept children with disabilities and offer scholarships*. Other Community organizations listed by focus group participants that have provided accessible recreational and social activities include the following:

- *Church is good.*
- *4-H.*
- *Parks and Recreation advocated to get an inclusion specialist. Any program in their book, they support the people.*
- *The YMCA will work with special needs and has scholarships available.*
- *The Senate Bill 40 Board has been very supportive in offering limited transportation to individuals who live in a natural home so they can attend certain recreational activities in the community.*
- *Bowling Alley owner and staff are very good to us.*

Segregated Programs that Provide Recreation (94 comments):

There are some segregated programs for people with disabilities that provide recreational opportunities. One focus group participant stated that *there is a very good Special Olympics program* in their community. There are also camps for individuals with disabilities. One focus group participant said that they send *30 people to Camp Wonderland*. Athletics programs are also available. One parent's *son is involved in DASA* (Disabled Athletes Sports Association).

Community Initiatives that Increased Recreation Alternatives (44 comments):

There are some community initiatives that increase community recreation options for individuals with developmental disabilities. One participant provided the example that *Hossetler farm is great. It is run by Mennonites and they have all kinds of animals, like a zoo*. Another community movie theater *provides free movies*. Another participant talked about the help received from a Regional Center. *With help from the Regional Center, we have been offered passes through the Centre for Swimming*.

Other Comments About Help with Recreation:

Some illustrative comments about help and supports received for recreational activities include:

- *We have dances occasionally. Everyone enjoys them.*
- *We used to have Bluegrass Day on the square. I have never involved my son in things like that.*

COMMUNITY RESOURCE/SUPPORT ISSUES

The next section of the survey looked at types of generic community resources/supports people with disabilities are likely to access in their community. The types of community services examined included: (1) civic organizations; (2) faith-based organizations; (3) social service organizations; and (4) family and friends. The type of community resource/support that was *most likely* to be used was *family and friends* (60.5%). The type of community resource/support least likely to be used was *civic organizations* (9.7%). (See Table 19.)

Table 19. Most and Least Likely Community Resource/Support Choice

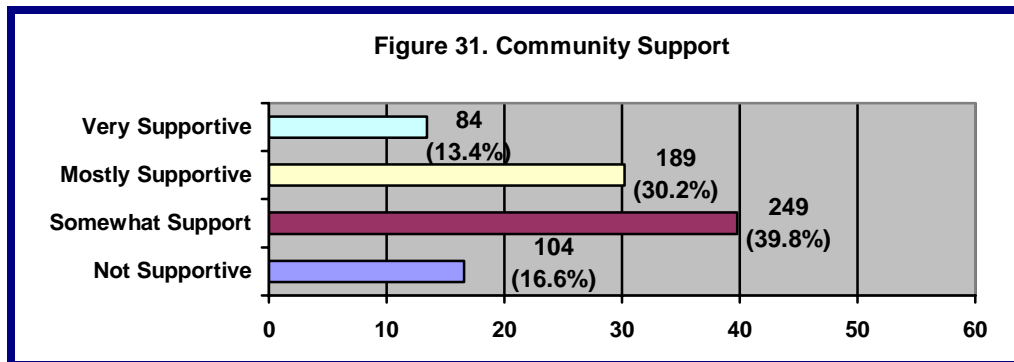
Item	Civic organizations	Faith-based organizations	Social service organizations	Family and friends
What type of community resources are people most likely to use?	47 (9.7%)	86 (17.8%)	58 (12.0%)	292 (60.5%)
What type of community resources are people least likely to use?	270 (60.4%)	56 (12.5%)	89 (19.9%)	32 (7.2%)

The adequacy of the types of generic community resources/supports was evaluated on a four-point scale (1=Inadequate ...4=Excellent). Over 76% of the respondents rated *family and friends* as *good* (38.4%), or *excellent* (38.2%). *Family and friends* had a mean of 3.10. Faith-based resources were seen as *good* (37.7%), or *excellent* (18.4%) by approximately 56% of the respondents. Civic organizations were rated as *inadequate* by 40.4% of the respondents. (See Table 20.)

Table 20. Adequacy of Community Resources/Supports

Item	Inadequate	Fair	Good	Excellent	Mean
Civic organizations (507)*	205 (40.4%)	180 (35.5%)	98 (19.3%)	24 (4.7%)	1.88
Faith-based (555)*	74 (13.3%)	170 (30.6%)	209 (37.7%)	102 (18.4%)	2.61
Social organization (517)*	134 (25.9%)	177 (34.2%)	159 (30.8%)	47 (9.1%)	2.23
Family and friends (602)*	28 (4.7%)	113 (18.8%)	231 (38.4%)	230 (38.2%)	3.10
Scale: 1=Inadequate...4=Excellent *Total number responding					

Figure 31 indicates how respondents rated how supportive their community is towards people with disabilities. The rating was on a four-point scale (1=Not Supportive...4= Very Supportive). Overall, 70% of the respondents reported the support they receive from their community as *mostly* (30.2%), or *somewhat supportive* (39.8%).

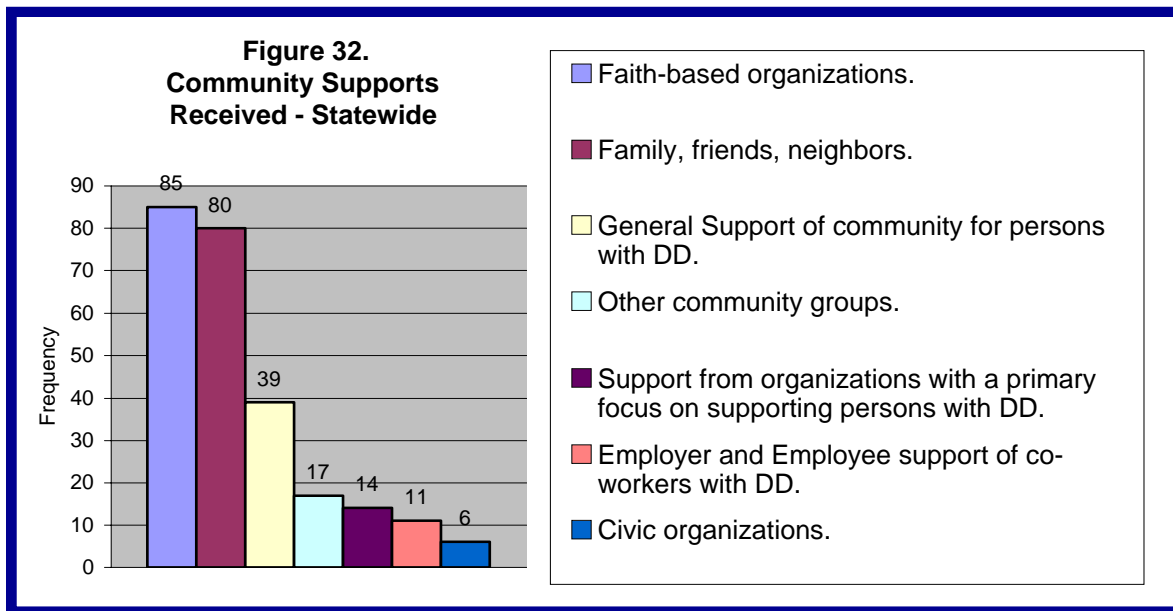


Community Support Focus Group Discussion

Focus group participants were asked to discuss the issues they have with community support, including: (1) Describe the support people with disabilities receive from other people in your community such as friends, neighbors, and clergy, and (2) How would you describe the general attitude in your community towards people with disabilities?

Community Supports Received:

Many focus group participants found support in faith-based organizations (85 comments) and with family, friends, and neighbors (80 comments). Another important area of support was general support of community for persons with developmental disabilities (39 comments). Detailed comments for these themes are found below. Figure 32 represents the overall findings for community supports received.



Faith-based Organizations (85 Comments):

Several focus group participants stated that they felt welcome and accepted in their church, as well as supported in many different ways. They also found transportation services and accessibility to be helpful. Detailed comments related to faith-based organizations follow.

Acceptance: Focus group participants felt that they were accepted in their church. One individual stated that *churches here are very receptive to people with disabilities*. Others said that *church is good to include people with disabilities, my church welcomes everyone, and church accepts her*. One self-advocate said *I go to the big church in Elsie. I go to Bible School and Bible Class and cookouts. They treat me good. They are nice to me*. Another added that *church people are friends and my Pentecostal Church helps me a lot. I sing and they enjoy me. They teach me how to play the organ and drums*.

Transportation: Some of the churches offered transportation to people with disabilities. One person said *their friends from church provide transportation*. Another said *a consumer I know of has good luck with transportation through his church – creative transportation*. Other positive comments were:

- *Our priest and sister are good about visiting him and picking him up to go to church if we need them to.*
- *Church comes and gets my daughter.*
- *They see that we can get to church and to activities if need be.*
- *I pick up a girl that is disabled every Sunday morning. She sits up front with me and I feel like the church is really good.*
- *Church vans for transportation and church members for childcare.*

Two comments were made that showed some concerns. One person said that *the churches are great for transportation if there are no accessibility issues and are very supportive of people with DD*. Another stated that *our church has transportation, but don't have a wheelchair lift*.

Support: Support was found to be a very positive aspect of the faith-based organizations. Not only did they provide support in terms of physical needs but also in the area of emotional needs. A couple of comments people made regarding the physical support they have witnessed were that *churches have supportive programs to aid in back to school needs* and that *churches offer food baskets at Thanksgiving and Christmas*. One mom found their church to be particularly helpful. *Our church has done a good job with our daughter. They even provide respite for us*. The emotional support people received was seen in many different areas. One person said that *our pastor is a doc of psychology. We took him to IEP. He's given us advice and stuff like that. Worked with lots of kids*. Another person has seen the positive effects in their child. *Church has been good for support, my child is happy and laughs*. Another person stated that *our church is a huge deal. I see that as being those who love him and support him and will always be there*. This person has experienced both the physical support and emotional support. *My church is a support to me. When my mom passed away, they brought over lots of food. Some of the church members are still bringing over food. Some people have offered to stop in and help if I need it*.

Accessibility: Some of the churches have tried to make their facility accessible to people with disabilities. One person shared their experience, *there's a church on Hwy 63, starting a support group for people with disabilities. Children's church have put in a ramp to make it accessible for my child*. Someone else added that *another church has done ramps. Two churches have tried to make restrooms accessible. Have approached people and talked to them to make them feel more comfortable about people with disabilities*. Another church had this to offer: *The pastor is good. They have a separate classroom for people with disabilities and adults with disabilities. They have had that class all the time I have gone there*.

Family, Friends, Neighbors (80 Comments):

Focus group participants felt that their family, friends and neighbors were helpful and supported them. Family members offered support by *shopping and paying bills*. One person felt that their life depended on their family. *If not for family I wouldn't survive*. Friends were also helpful. *Friends help with laundry and help find things*. *My friend takes me for rides after church*. Neighbors were found to be extremely helpful. Following are some of the comments made by focus group participants about their experience with their neighbors:

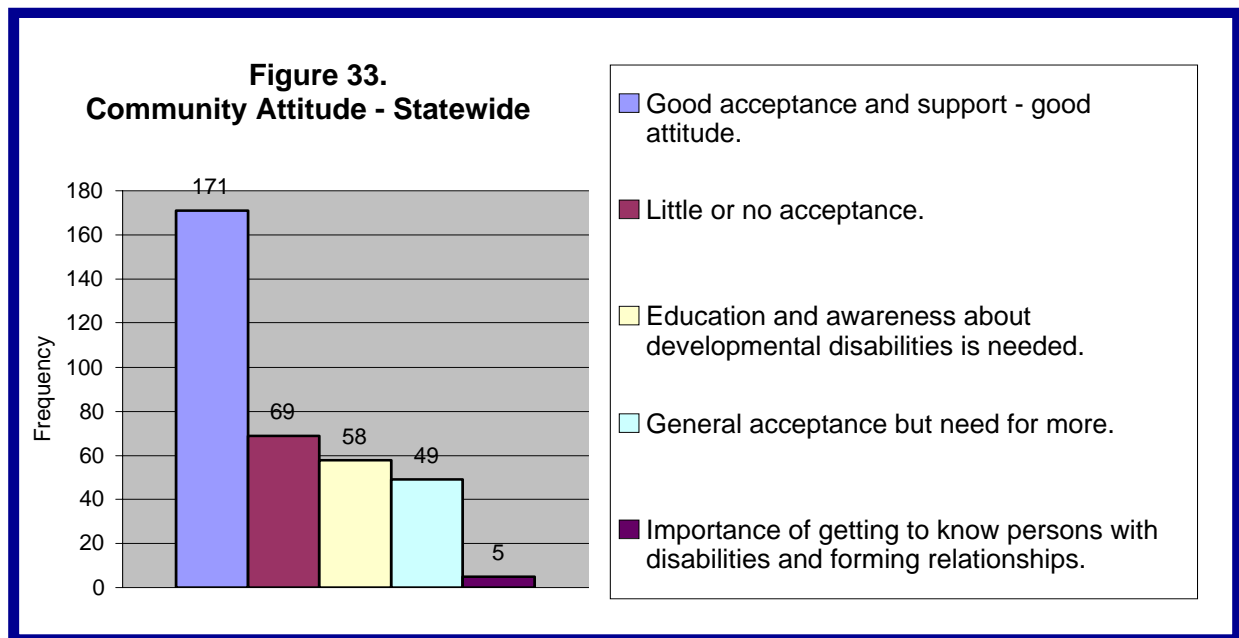
- *Neighbors have been very supportive.*
- *Neighbor that baby-sits for free.*
- *Neighbors help them go grocery shopping.*
- *Neighbors are very helpful*
- *My neighbors "adopted" me and help me with laundry, and also help me by giving me transportation to appointments and the grocery store.*
- *Gets help from neighbors. Help her get commodities.*
- *My neighbors help me when I need something. They have cooked dinner for us.*
- *Neighbors always wanting to help us out, help fix the porch, helped build ramp.*

General Support of Community for Persons with developmental disabilities (39 Comments):

Focus group participants had positive things to say about the general support in the community for persons with developmental disabilities. Some people shared their personal experiences: *People will see me walking to work and they will stop and give me a ride; most people are courteous and will stop traffic to let me cross (uses wheelchair; and I have a real good friend who is a pastor and he always stops to say hi. People are always asking if I need help*. One person shared this story: *My son uses a wheelchair; My daughter made an observation once; She used one of his wheelchairs in a store; She told me she liked using his wheelchair because lots of people asked her if she needed help and talked to me; She said people are really nice when you are in a wheelchair*. Some general comments people made were: *we have a great community area support; people are very respectful and accommodating; I have friends in the community; we feel supported; and employers hire individuals with disabilities*.

Community Attitude:

Some of the topics focus group participants discussed were good acceptance and support attitude (171 comments), little or no acceptance (69 comments), education and awareness (58 comments), and general acceptance (49 comments). The themes and comments are given in detail in Figure 33. Detailed comments can also be found below.



Good Acceptance and Support – Good Attitude (171 Comments):

Many people expressed that they feel accepted and supported in their community. Comments such as this one were made, *we feel welcome in our community and a part of our community*. Another added, *we feel that the community has a very good attitude toward us, and we feel that the community can offer things to make us feel good*. Other comments about good acceptance and support are provided in detail below.

Acceptance: Focus group participants felt accepted. Some of the comments they shared about acceptance were: *Community members in the area are very accepting; always accepted in community and church; church is accessible and very accepting; community supports people with disabilities by including them; and people know daughter and she is accepted in the community and church*. One person shared this insight, *the Community Attitude has really changed. They talk with the clients, the clients attend church and everyone is glad to see them*.

Advocacy/Awareness: Some people have noticed that *awareness is good*. One person shared, *my co-workers have taken it upon themselves to educate others about acceptance because of their relationship with my child. They have taught their children to watch out for him*. Also, *local newspapers will publish good articles in favor of disability issues*.

Supportive & Helpful: Focus Group participants felt that *overall there is positive support in the community for people with DD and that neighborhoods, community associations, and churches are extremely supportive*. One person said, *our community sticks together, looks out for those who need a little extra care*. Another person said that she was a part of (her) community. *Not looked at funny or treated differently. People bring diabetic food to her since she is diabetic*.

Little or No Acceptance (69 Comments):

Focus group participants shared many different comments on their experience with having little or no acceptance from others. Many people showed fear toward them, ridiculed them, or made them feel “different”. They felt that *people don’t treat us right and there is still a stigma out there*. Additional comments in these areas are in detail below.

Fear: People found the *fear factor/ignorance factor* to be a big issue. One person noticed that *some people still shy away from you*. And another noticed that *people are often uncomfortable around people with disabilities*. One person shared about a different type of fear stating that *churches may not reach out in some instances for fear of additional responsibilities they may have (transportation, accessibility, etc.)*.

Picked-on & Ridiculed: Many people have experienced being picked-on and ridiculed by strangers as well as by people in their neighborhood, workplace, school, and church. One mom said that *in the grocery store I have to protect my child because kids are making fun of him*. Another person shared, *I have been ridiculed because of my sight. On average people look at people with disabilities like we are leaches and I don’t understand it. People with disabilities are just like everyone else they just have obstacles to overcome. Also, people heckle from cars toward many people with disabilities in the community*.

“Different”: Many people with disabilities are looked at as being different. One mom said *my daughter doesn’t like to go to Wal-Mart because everyone stares*. Another mom *Got frustrated. She had feeding tube. People look at you like “what kind of drugs was mom on when she was born.” She is mine. Sit in restaurants and people stare. Look at you like you did something wrong*. One person shared, *I really don’t go out much, people gawk sometimes. I only go out about once a month and when I go grocery shopping*.

Education and Awareness about Developmental Disabilities is Needed (58 Comments):

Some individuals with disabilities have found a *lack of awareness, a lack of education, and a lack of understanding* in their community. Some people *stare because of differences*. One person shared *My grandson has a t-shirt that says, “if you stare at me long enough I might do a trick”*. Many focus group participants felt that they were misunderstood and shared these comments: *Too many stereotypes – no opportunity to prove what you can do; they think we are stupid sometimes; and because of my chair I couldn’t get a job – people see the chair instead of the person*. Some participants felt that *People want to be helpful, they just don’t know how*. And that *people are truly concerned, but do not know how to accommodate*.

General Acceptance but Need for More (49 Comments):

Focus group participants felt that overall *most people are accepted in our community but some people don’t accept our disabilities*. A variety of topics were covered in this area and the following list represents the viewpoint of the participants:

- *I would like to see organizations provide personal involvement rather than just monetary donations.*
- *The community could be more open.*
- *There is no consistency in faith-based organizations to help the handicapped on a regular basis.*
- *They are part of the community but are not noticed much.*
- *They don't go out of their way to specify person with disability but they are included.*
- *Son doesn't have any close friends but everyone treats him nice. We find that most people are friendly to our son and would be protective, but are reluctant to include him in activities.*
- *In the past was very negative, but with the advocacy work that parents have done over the years, it is getting a little better.*

Other Community Support:

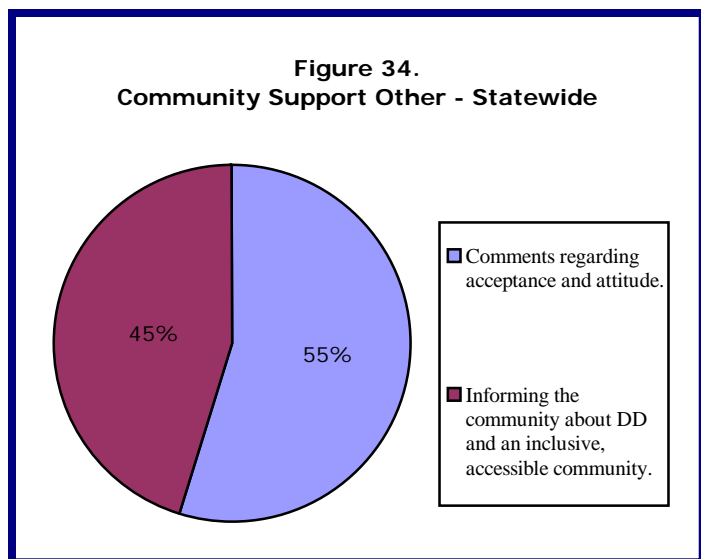
Focus group participants offered additional comments regarding acceptance and attitude and informing the community about DD and an inclusive, accessible community. Following are detailed comments along with Figure 34 showing the results of these issues.

Comments regarding acceptance and attitude (29 Comments):

Additional comments people made regarding acceptance and attitude ranged from very positive to negative. A fun, positive story one person shared was, *Have worked with family for at least eight years. The child with a disability in a small area and is in a wheelchair. Child went out for and made the cheerleading squad. This happened because the child, parents, teachers, and the community was educated.* On the negative side, one person felt *I sometimes feel like a nobody.* Another was uncomfortable because *at bigger towns and malls people sneer and comment.* Another young lady shared *I feel I don't have community support I have lost my independence my family is not supportive.*

Informing the community about developmental disabilities and an inclusive, accessible community (24 Comments):

Many different thoughts were shared about informing the community about developmental disabilities and an inclusive, accessible community. One person shared that the *OCSS started a program with the Osage County Library. OCSS has set aside money to purchase books regarding special needs and then donates them to the library. The library feels this has become a very successful program.* Some recommendations to help educate people were to *have someone develop a handicapped resource handbook for social workers and others to distribute*



to families so they can know what is out there, to have classes available to teach volunteers how to deal with the handicapped and how to transport people to and from chairs, and have a handicapped education program where the owners of businesses are set in wheelchairs and get to experience using a chair in the building. A problem that came up several times was accessibility. One parent noted, *Cannot push my son, my neighborhood streets are not accessible*. Another mentioned, *Let them see for themselves how steep the ramps are, how poorly the bathrooms were designed and how hard the doors are to open*. One person suggested that *they should put yellow lines for wheelchairs, bikes, etc. for people to be able to travel along roadside*. Another suggestion was that *they should designate special crossings for people with disabilities*.

SAFETY AND QUALITY ASSURANCE ISSUES

Survey respondents were asked if they were aware of any incidents that affect the health, safety and quality of life of people with disabilities in their community. Incident items included: 1) physical abuse/neglect; 2) sexual abuse; 3) financial abuse; 4) violation of human or legal rights. Respondents were asked to check the incident item if they were aware of any person with a disability in their community who had experienced that type of incident. Table 21 lists the findings.

Of the 737 people surveyed, about 20% were aware of some physical abuse/neglect in their community; 16% were aware of sexual abuse; 21% were aware of some type of financial abuse; and 24% were aware of a human or legal rights violation.

As a follow up question, respondents who had checked one of the incident items were also asked to share their perception about how that particular type of incident had been handled. As can be seen in Table 23, more people responded to the follow up question than had responded to the original question. For some reason, a number of survey respondents did not understand it to be a follow up question and answered it anyway.

Even though this discrepancy exists, and readers are advised to take it into account, Table 22 is included because it still provides an indication of survey respondent's perceptions on how well the above types of incident items are handled. Additionally, because the handling of these types of incidents requires a degree of discretion, it is also important to recognize that respondents' perceptions of how these incidents are handled may not necessarily reflect what actually occurred to address them.

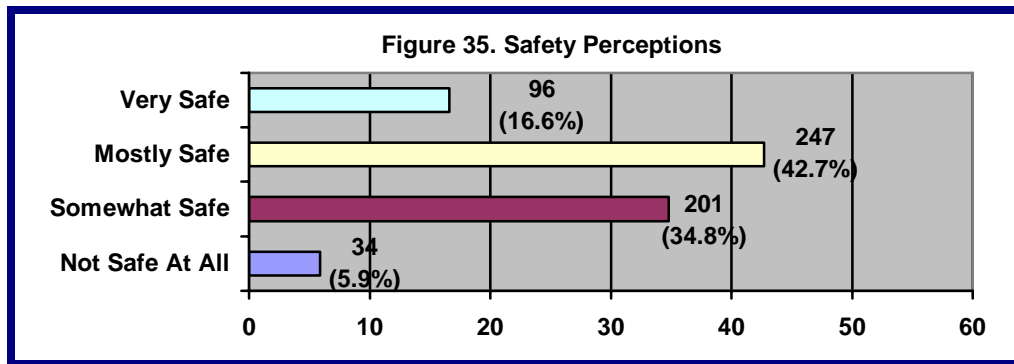
Table 21. Awareness of Safety Concerns

Item	
Physical Abuse/Neglect	150 (20.4%)
Sexual Abuse	118 (16%)
Financial Abuse	155 (21%)
Violations of human or legal rights	177 (24%)
<i>(Checked numbers per 737 total respondents)</i>	

Table 22: How Safety Concerns Were Handled

Item	Not at all	Not well	Well	Very well	Mean
Physical Abuse Neglect (249)*	66 (26.5%)	99 (39.8%)	52 (20.9%)	32 (12.9%)	2.20
Sexual Abuse (203)*	53 (26.1%)	69 (34.0%)	58 (28.6%)	23 (11.3%)	2.25
Financial Abuse (241)*	66 (27.4%)	94 (39.0%)	56 (23.2%)	25 (10.4%)	2.17
Violations of human rights (245)*	83 (33.9%)	77 (31.4%)	57 (23.3%)	28 (11.4%)	2.12
Scale: 1=Not At All...4=Very Well *Total number responding					

Survey respondents were asked to rate how safe people with disabilities were in their community. Figure 35 reflects their responses. The rating was on a four-point scale (1=Not Safe At All...4= Very Safe). Almost 78% of the respondents saw people with disabilities as being *mostly safe* (42.7%) or *somewhat safe* (34.8%) in their community.

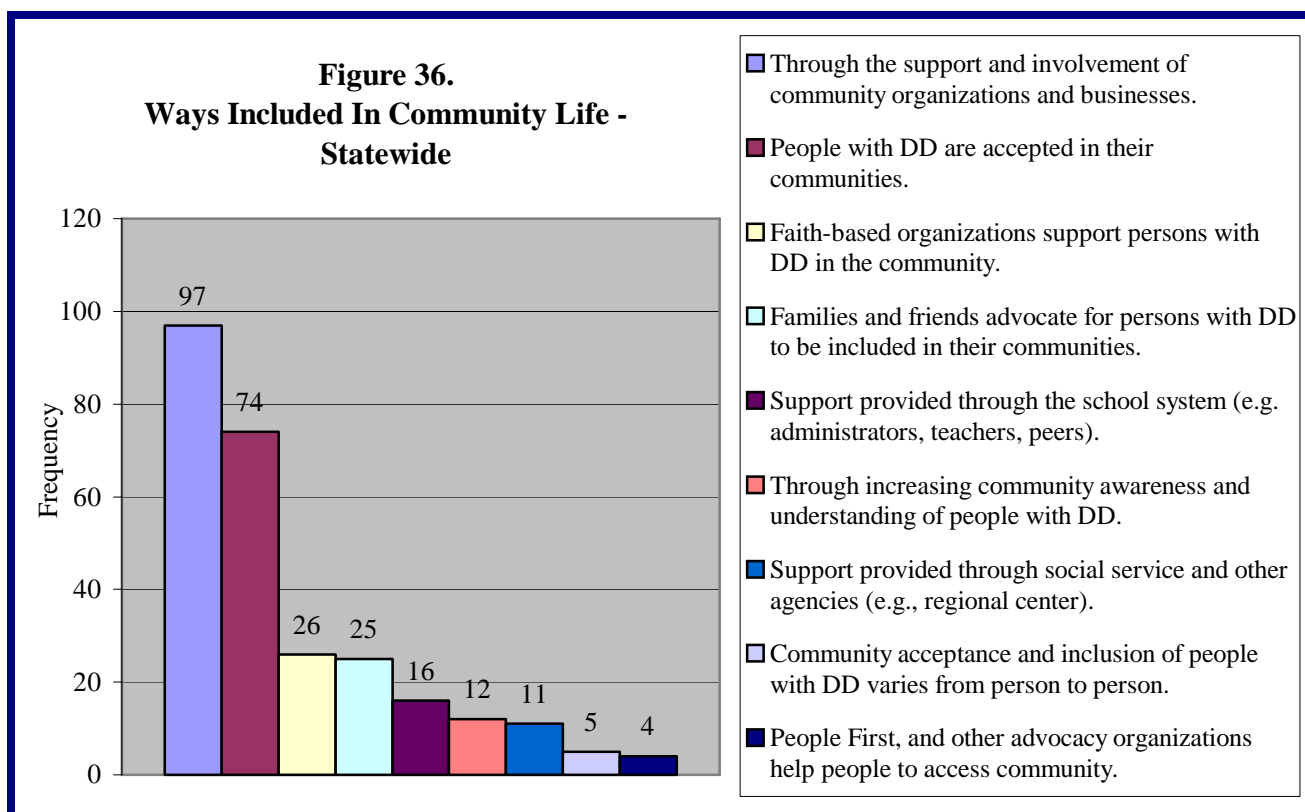


Quality Assurance Focus Group Discussion

Focus group participants were asked: (1) How are people with developmental disabilities included from participating in community life; and (2) How are they excluded or isolated? (3) How are people with disabilities, and their families in your community included in the planning processes that effect their lives? Quality Assurance related issues from the focus group are provided in detail below.

Ways People with Developmental Disabilities Have Been Included:

The focus group participants discussed ways that people with disabilities have been included in community life. The most common theme was through the support and involvement of community organizations and business (97 comments). The most common themes from the focus group are provided in detail in Figure 36 illustrative comments from the top common themes about ways individuals with developmental disabilities have been included are also provided in detail below.



Through Support and Involvement of Community Organizations (97 comments):

Several comments were made about the support and involvement of community organizations and businesses in including people with developmental disabilities in community life. One individual at the focus group stated that *friends of the Workshop has been good. They helped raise about \$9,000 dollars with the chili dinner and Christmas trees. All the money goes towards recreation and to improve the individual's lives.* Another adult at the focus group provided a personal example, *I felt very included when I was active in the local democrat group with electioneering, working the polls, and helping to campaign for various candidates.* A parent stated *my daughter started playing basketball with the local Optimists Club and it is working well.*

People with Developmental Disabilities are Accepted in Their Communities (74 comments):

Several focus group participants simply stated *our community is very accepting.* One way a participant feels accepted in the community is through their *church, family, and schools.* One parent feels that *acceptance of individuals with disabilities has gotten much better.* In one small community individuals with disabilities hold prominent positions. *We have some prominent people in town who are developmentally disabled and they have been accepted.* Another focus group member discussed the ease of acceptance in a rural area. *In a small town, everyone knows everyone. Small towns don't have as many barriers, you know everyone, it is more accepting.*

Faith Based Organization Support (26 comments):

Many faith-based organizations provide support for people with developmental disabilities. One focus group participant stated *people are included well in churches*. A few participants gave examples of this. One parent stated *my daughter has been exposed to a church where they were accepting of her, but had never been around others with disabilities*. Another parent stated *I think we have to allow our kids out in the community. My son is very well accepted at church*.

Family and Friends Advocate for Persons to be Included in Community (25 comments):

Focus group participants discussed the role of family and friends in advocating for people with disabilities to be included in the community. One focus group participant stated that as a parent, *you need to be your child's own best advocate*. Another participant observed that community inclusion depends on *parents pushing and pushing for their children*. Generally, *people are included in the community at the insistence of the parents, because they don't keep their loved ones behind closed doors*. The issue of community inclusion should be brought to the forefront *the community needs more education* on the subject in order to assist with inclusion. The younger generation is becoming more knowledgeable about the subject. For example, *younger parents are now thinking more inclusively. It is an evolution of services*.

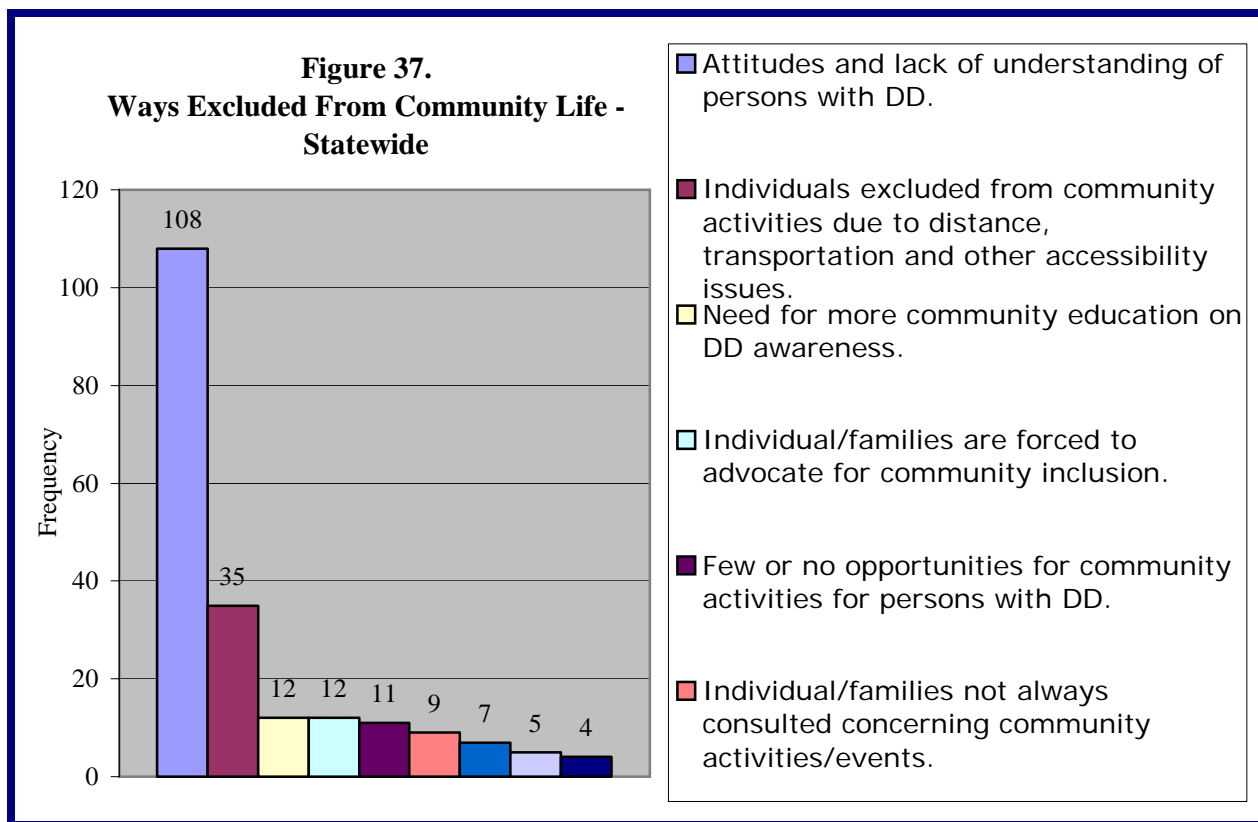
Other Comments about Inclusion in Community:

Other comments that are illustrative of ways that people with disabilities have been able to participate in the community are:

- *Some people with disabilities can vote.*
- *The Eagles club has dances for people with developmental disabilities and will let us use their building for activities.*
- *The Community Counseling Center has a clubhouse for people with mental illness.*

Ways That Individuals with Disabilities Have Been Excluded from Community Life:

The focus group participants discussed ways that individuals with difficulties have been excluded from community life. Attitudes and lack of understanding of persons with developmental disabilities (108 comments) was a common theme among the participants in the focus groups. The common focus group themes are presented in detail in Figure 37. Illustrative comments of the top common themes are presented in detail below.



Attitudes and Lack of Understanding (108 comments):

Attitudes and lack of understanding about people with disabilities leads to exclusion from the community. One parent commented that *it is hard for my son. It is hard to find things that he isn't excluded from* because of community perception. Related comments about attitudes and perceptions of people with disabilities follow.

Teacher and School Perceptions: School is an important part of community life. Children with disabilities and their parents often find themselves excluded from this part of community life because of school and teacher perceptions. Illustrative of this is one comment from a parent *the schools fight you when you want your child included*. A parent discussed their experience with inclusion. *When we tried to mainstream our son into the school system, letters were sent out to the parents. One parent did not want my child to associate with their child*. Another parent added *the school has stopped asking my son to be in plays*. One focus group member commented, *I think inclusion [in schools] doesn't happen because of fear. [You] just try to explain to students and school officials*.

Community Exclusion: Focus group participants felt that the community at large often purposefully excludes them. One participant stated *the community does not always include persons with disabilities in planning*. Another added that *they [people with disabilities] are divided. Generally they are excluded. They accept them, but they are not included in activities*.

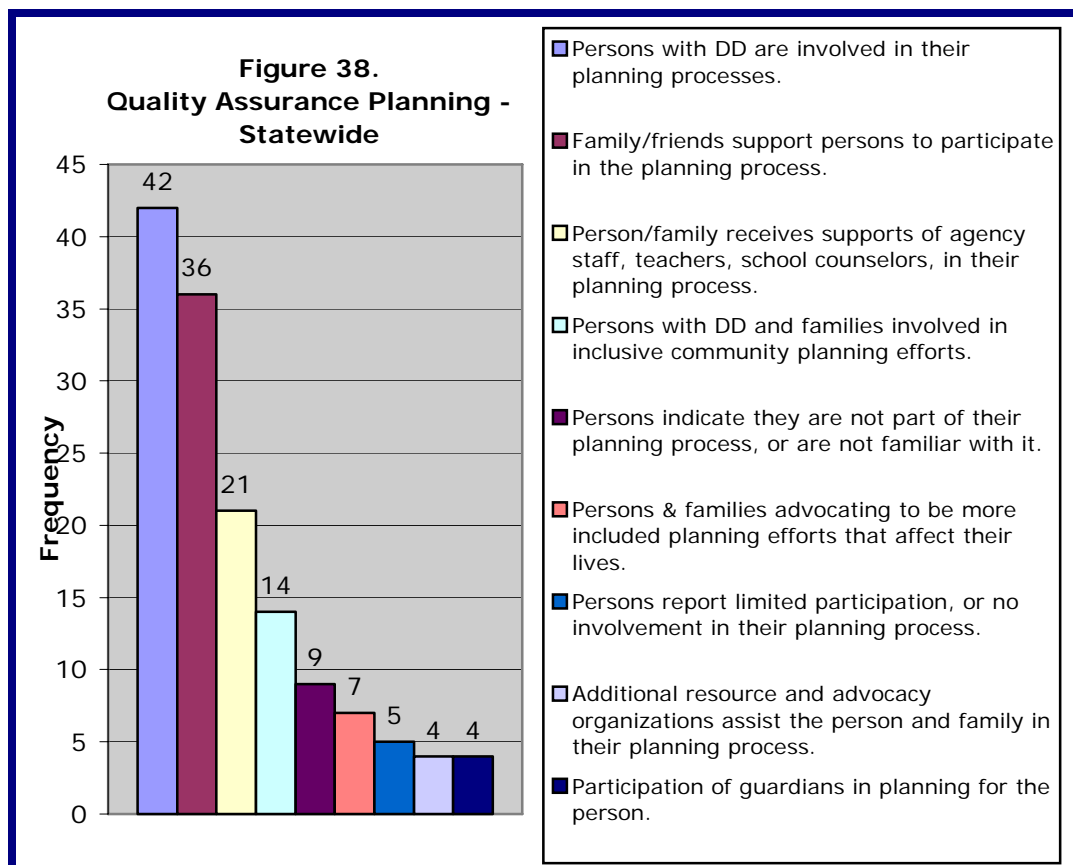
Attitudinal Barriers: Attitude is also a barrier for some people with disabilities. Focus group participants state that when they go out in public *people stare*. One individual stated that *I feel excluded because I think that people think I am weird*. Sometimes people with disabilities don't want to go out in public because of this. *I have seen people with developmental disabilities isolate themselves. It really depends on the person.*

Individuals Excluded from Community Because of Transportation (35 comments):

Focus group participants stated that distance and transportation issues often exclude them from participating in community life. One participant commented *I don't feel like I can be included in my community due to transportation issues, and I don't drive*. A parent in the focus group echoed this statement, *we are really isolated. It is too rural. There is nothing here. We are isolated in Daviess County*. Transportation and distance limits individuals from doing activities in the community. *Transportation isolates the opportunity for volunteering* for example.

Inclusion of People with Disabilities and their Families in Life Planning:

A common theme among the participants was simply that persons with developmental disabilities are involved in their planning processes (42 comments). The focus group participants also discussed ways that they or their family members are included in the planning processes that affect their lives (36 comments). Common themes from the focus groups are presented in detail in Figure 38. Illustrative comments from the top themes are provided in detail below.



Involved in Planning (42 comments):

Several focus group participants discussed their involvement in the planning process. One parent stated that *for my son, we include him in planning his activities and goals through Futures Planning and a micro-board*. Another individual commented *I am included in the planning process. If you live in a group home, we have an opportunity to be part of our plan*.

Family and Friends Support Planning (36 comments):

Family members and friends play an important role, not only in the planning process, but in the lives of people with disabilities. One parent discussed the importance of being involved. *I have to be a very proactive mom and say what I have to say to get things done*. Another focus group participant described the way in which his family is involved in planning *if I want to make decisions then I need to be aware that I need to use my head and concentrate. If not, my family member takes care of it*.

Support from Agencies and Schools (21 comments):

People with disabilities also receive support from agencies and schools in the community. *Person Centered Planning* is one means through which this occurs. One participant stated that *families and consumers can participate in Person Centered Planning with service coordinators*. Service Coordinators are very important in the process. *My service coordinator helped me get moved into my apartment*. Another focus group participant stated that *the service coordinator can make a huge impact in how people work in the system*.

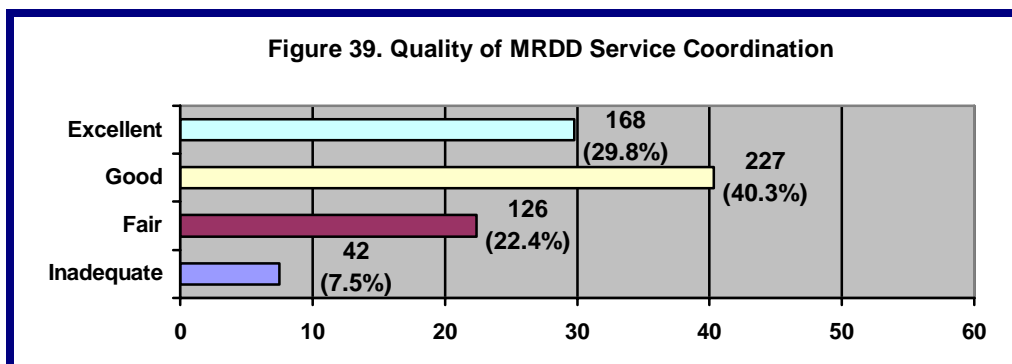
Other Comments about the Planning Process:

Some other comments about the planning process are:

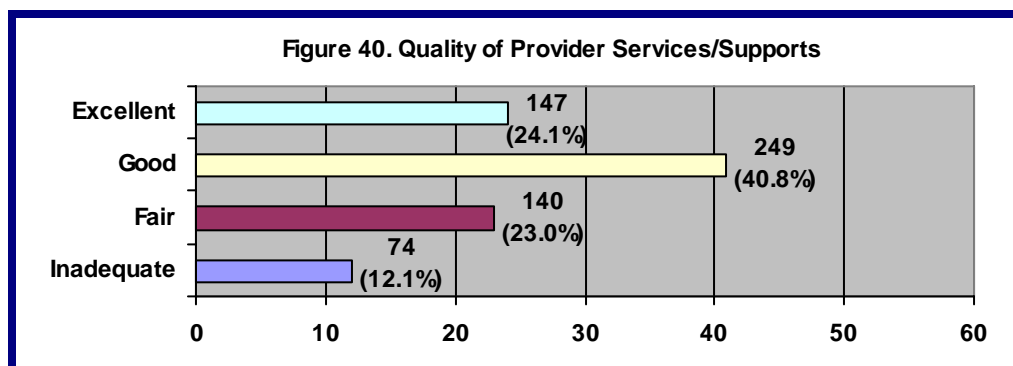
- *Any services or assistance that is offered is very structured. There is no room for spontaneity.*
- *In community planning if someone has a disability it is not even thought of. It is a small town, it is not even thought of.*

SATISFACTION WITH SERVICES

Survey respondents were asked how they would rate MRDD service coordination/case management services. Figure 39 shows how respondents rated this service. The rating was on a four-point scale (1=Inadequate...4= Excellent). Service coordination was seen as *good* (40.3%) or *excellent* (29.8%) by over 70% of the respondents.



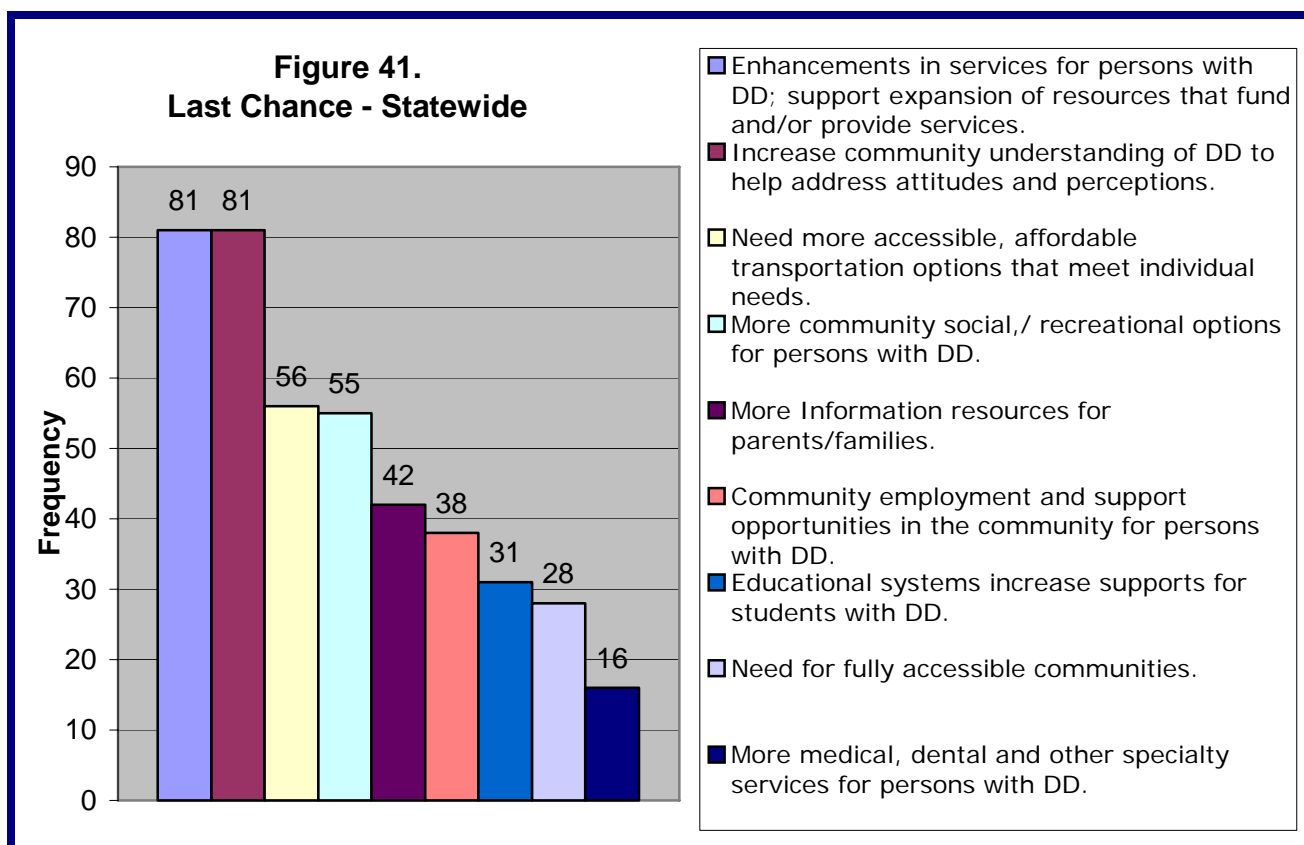
Respondents were also asked to rate the quality of services/supports that they, or others had received from providers in their community. Figure 40 shows how respondents rated the quality of provider services/supports. The rating was on a four-point scale (1=Inadequate...4=Excellent). The quality of provider services/supports was rated as *good* (40.8%) or *excellent* (24.1%), by almost 65% of the respondents.



Last Chance Focus Group Discussion

Focus group participants were asked “If you could change one thing in your community that would make it better for people with disabilities, what would it be?” The focus group discussions on this question are reviewed in detail in this section.

Participants were interested in the enhancements in services for person with DD, support expansion of resources that fund and/or provide services (81 comments) and also to increase community understanding of DD to help address attitudes and perceptions (81 comments). Other areas of interest were more community social/recreational options for persons with DD (56 comments), need more accessible, affordable transportation options that meet individual needs (55 comments), more information resources for parents/families (42 comments), educational systems increase supports for students with DD (38 comments), community employment and support opportunities in the community for persons with DD (31 comments), and need for fully accessible communities (28 comments). Detailed comments for these topics are found below. Figure 41 represents these overall findings.



Enhancements in services for person with developmental disabilities, support expansion of resources that fund and/or provide services (81 comments):

Many issues were covered under this topic. One person expressed *We need more funding for services that people with disabilities need but aren't getting.* Another person added that *they should pay for what people need, not just what is on the list with Medicare or Medicaid.* Other comments made were: *It would be nice if Medicaid could be increased; it would be nice to have more money; and more funding to help with things.* Another person suggested that *we need less bureaucracy and processes should be simplified – increase customer services – families seem to be isolated – not much networking.* People also felt there needs to be *proper training for individuals who work with those with disabilities and respite care for all.*

Increase community understanding of developmental disabilities to help address attitudes and perceptions (81 comments):

The overall feeling about increasing the community's understanding of developmental disabilities is there needs to be *community awareness.* *Educating people on disabilities* was another topic of importance. There needs to be *better education for those who don't have experience with people having disabilities and education of the general public and schools about developmental disabilities.* *Education changes attitudes.* Another person added that *acceptance is important because then a lot more opportunities would open up for activities and recreation.*

More community social/recreational options for persons with developmental disabilities (58 comments):

Many people expressed that *there needs to be something for them to do – be included in the community*. One person recommended having *activities just for the disabled because they can't compete in sports with their peers*. Other suggestions were: *More activities for adults; more community activities; more dances; more leisure activities; more relationships with people; more programs for kid; more activities year round; and more places like the Life Center*. One child wanted *more activities that I could do on my own without parents bringing me*.

Need more accessible, affordable transportation options that meet individual needs (55 comments):

Many participants expressed concern about having accessible, affordable transportation options. *Transportation is a huge need... If you do not have it you do not get to come out*. Things people need are: *More transportation options; gas to get around; better transportation; inexpensive/affordable transportation; transportation from their homes; and safe dependable transportation*. One person recommended *a transit system that works at night and willing to take people who have a disability when they need to go*. This person also added *If I had a way to go I'd never be at home!*

More information resources for parents/families (42 comments):

Focus group participants would like to see *more public awareness and education to the needs and resources of people with developmental disabilities*. *More information sharing... will help parents*. They need to find a way to *unite families to share information and not feel so isolated*. One person recommended *having parents join together and share information with each other*. Another added *More awareness of everyday families and of us knowing who each other are*. Additional suggestions made was that there needs to be *a directory for towns that would list services available here in the community or county with numbers to call, having a Central Clearinghouse of information, and having a list of services – what is genuinely available*.

Educational systems increase supports for students with developmental disabilities (38 comments):

Some of the suggestions regarding educational systems were to *have more teachers in classrooms, more one on one in schools, school to have more knowledge, tutors for children to learn better or an aide in the classroom, and more services and more education for people*. One participant pointed out that *education is the thing... you have to teach the teachers before they can teach the children... and if we don't have the education... there is nothing*.

Community employment and support opportunities in the community for persons with developmental disabilities (31 comments):

Focus group participants discussed many different needs in the area of community employment and support opportunities. Some people mentioned there *needs to be more jobs available for slower paced workers, they need more work places for people, need opportunities for supported employment, and need more work places for people with disabilities.* Other recommendations were to *have job coaches on the job site, to have sheltered workshops pay minimum wage to their employees, and to have more work opportunities and more supported employment options.*

Need for fully accessible communities (28 comments):

The need for fully accessible communities is clear. Recommendations people made were to *have better accessibility to places, sidewalks that are accessible, handicap accessible doors, accessibility in restrooms, more automatic doors for public buildings, more ramps, and to make the stores, sidewalks and community more accessible.* One person suggested *every school and playground should be accessible from the beginning.* Another comment was to *give more tickets to selfish people who park in handicapped spaces and use the money collected from the tickets to pay for automatic doors in city hall, the county courthouse and other public buildings.*

SUMMARY

In the years 2004/2005, the Missouri Planning Council for Developmental Disabilities, with assistance from Regional Advisory Councils, conducted a statewide needs assessment. Individuals with disabilities and family members in each of the 11 MRDD Regions in Missouri completed a written survey. The majority of the 737 respondents were family members (63.5%).

Over two thirds of those responding had received services (68.9%). A total of a 127 focus groups were held in 110 of Missouri's 114 counties. There were 975 individuals who participated in the focus groups, 41% (400) were individuals with a developmental disability, and the other 59% (575) were family members. Slightly over two thirds (64%) of the focus group participants received services. The following summarizes the results of both the written surveys and the focus groups.

Employment Issues:

People with disabilities were reported to most likely work in sheltered employment (42.2%) or non-employment situations (37.3%), and reported least likely in regular jobs in the community (66.7%). Over 50% rated options related to regular jobs in the community as inadequate (51.8%). Community employment options with paid support were also seen as inadequate by 40.2% of the respondents and only fair by 27.9%. Respondents split on how they perceived the adequacy of sheltered employment. A little over 45% saw sheltered employment as inadequate (21.1%) or fair (24.4%), while 55% saw it as good (34.6%) or excellent (19.9%). About 71% reported that opportunities for regular or supported employment were either inadequate (42.4%) or fair (29%). Focus group respondents identified *few or no job opportunities*, and *employer perceptions, attitudes and lack of understanding*, as the top two employment challenges. Some other challenges identified included, *lack of transportation, lack of employer supports, concern with capacity of employment provider, and a mismatch with the person's vocational interests or abilities/skills*. By far, the number one employment help and support identified by focus group members was *sheltered employment*. Some other employment helps/supports reported being received included, *employment supports through public/private county and local organizations and providers, regular jobs obtained through typical supports, and community employment with paid supports*.

Residential Setting Issues:

The most typical residential setting was reported to be at home with family or friends (57.4%). A place of their own was seen as not available (26%) or only somewhat available (54.8%). At home with family or friends was seen as the most available source (79%). Community based housing/living opportunities was reported by the majority of respondents as inadequate (39.2%), or fair (32.3%). The number one housing issue identified by focus group respondents was the, *lack of accessible, affordable, safe housing in the community*. Several other problems identified included, *need for more in-home supports and services, long waiting lists for HUD housing and other community programs, challenges of living on one's own in the community, and the impact of community and housing industry perceptions about persons with DD on availability of housing*. The two housing supports respondents cited the most were, *living*

with family, and support from, public programs, resources, and organizations that help with housing (e.g., HUD programs). Other housing supports identified included, persons living in their own home in the community with generic or paid supports, and community organizations, neighbors, businesses, banks, etc. that have provided housing supports.

Transportation Issues:

The transportation that people with disabilities were most likely to use was public transportation (47.1%). Special transportation (38.6%) and Self-transportation (37.1%) were respectively seen as the least likely transportation choice. Special transportation was reported as the most inadequate option (49.7%). Self transportation was the option most often rated as excellent by respondents (36.1%). When asked to rate the opportunities for community-based transportation for people with disabilities, 72% of the respondents rated it as *fair* (29.8%), or *inadequate* (42.6%). Without question, the most prominent transportation issue cited by focus group respondents was the *lack of availability of transportation, especially in rural areas*. Other problems identified pertained to, *cost to meet transportation needs, limited transportation schedules, reliable consistent transportation services (e.g., arrive on time) and vehicle accessibility*. Overall, transportation support received through *various public transportation providers or collaborations*, was discussed most frequently by focus group respondents. Other transportation supports identified included, *transportation resources offered through community agencies and organizations, family provision of transportation supports, volunteers to assist with transportation, and specialized transportation services for persons with disabilities*. When asked to rate the opportunities for community-based transportation for people with disabilities, respondents rated this as *inadequate* (42.2%).

Child Care Issues:

Child care was rated as most likely to be provided by family or friends (69.6%). The least likely by regular childcare providers (49%). Family child care received the highest rating of adequacy (68.7%). Segregated child care and regular childcare received the lowest (52.9% and 40.9% respectively). Opportunities for community based childcare for children with disabilities was rated as inadequate by 57.4% of the respondents, and fair by 16.1%. Focus group members stated that the most challenging child care issue was that there are *few or no options for childcare* in their communities. Some other child care problems revolved around *a lack of providers or sitters with specialized skills to support kids with a disability, systems requirements that may limit childcare services, lack of family/friends to provide childcare and excessive costs for childcare*. Focus group participants reported that they have received the most child care support from *family or friends who assist with arranging or providing childcare services*. Some other child care help came from *inclusive childcare providers, and communities providing funding resources to develop and expand childcare options, as well as respite supports*.

Early Intervention Service Issues:

The most common early intervention service utilized was First Steps (41.8%), the least were those through regular pre-schools. Over 61% of those responding rated the First Steps program as good (34.4%) or excellent (26.7%), and over 58% rated the Head Start program as

good (38.5%) or excellent (20.3%). Special needs pre-school was rated lowest (34.1% inadequate, 20.7% fair). Therapies were reported as fair or good by almost 59% of those responding. Over 73% reported that early intervention services were either mostly available (30.3%), or only somewhat available (43.2%) in their community. By far, Focus group respondents reported that they had received early intervention supports through the *First Steps program and other infant/toddler programs*, and *other community resources (e.g. churches, civic organizations) supporting early intervention services*. Other comments included that the *Parents as Teachers program offered supports for the child and family*, and *Head Start assisted in preparing child for school*.

Educational Service Issues:

The most utilized educational type was Special public school education (46.1%), followed by students who are included in regular public school education (33.7%). The least likely to be utilized was private/home education. The highest rated educational type was special public school education (good (37.6%, excellent 15.8%). Private/home education was seen as the most inadequate (34.8%) followed by state schools (29.7%). Inclusive educational opportunities were rated as not available (17.1%) or somewhat available (49.2%). Transition services were rated as not available (22.6%) or somewhat available (48.4%). Post-high school opportunities were rated as not available (37.4%) or somewhat available (40.5%). Focus group respondents overwhelmingly reported that *a lack of quality; individualized supports are minimizing student potential*. Additional challenges cited were *a lack of school knowledge of best practices supports for students with developmental disabilities, school personnel misperceptions/attitudes concerning learning capacity and support needs of students with developmental disabilities, and lack of resources limiting needed supports and services*. The majority of focus group members expressed that *students/families were satisfied with school services received*. Other examples of educational support cited include, *teachers and classroom aides supported the student to be successful, supports received from other agencies that assisted students, families, and school systems, and early childhood programs facilitated child's readiness for school*.

Health Care Service Issues:

Respondents were most likely to use a doctor's office for health care services (62.2%). Least likely locations to be used were residential health care centers (3.6%) and local health departments (3.6%). With the exception of residential health care centers, all other health care services were rated as inadequate or fair by over 50% of those who responded. Hospitals/emergency rooms were rated by almost 70% of the respondents as inadequate (30.0%), or fair (39.9%). Doctor's offices were rated as inadequate (20.5%), or fair (46.7%) by over 67% of the respondents. Interestingly, the health care services least used were the ones that received the highest adequacy rating. (Community health clinics, 32.3%; Residential health care centers, 45%; and Local health departments, 28.5%.) When asked about the availability of health care and dental services for people with disabilities, 39.9% indicated health care services in the community as *not available*, and 50% reported dental care as *not available*. Focus group respondents cited *public health insurance program (e.g., Medicaid) issues that impact persons with developmental disabilities* most often as a pressing health care challenge. Other problems identified were, *a lack of dental services in proximity to the community, lack of general medical*

resources close to the community, and lack of affordable private insurance and increasing coverage. Health care supports were received from doctors and other medical professionals. Another major support cited reflects that there is, no problem finding medical and/or dental care. Other supports received include, Developmental Disability service agencies that assist with obtaining health services; family, friends, church members, etc. that help get them to medical/dental care, and health care paid through Medicaid/Medicare.

Recreation/Social Opportunity Issues:

The most likely recreation opportunities in the community were special/segregated recreation and social activities/events (49.8%). Regular community sponsored activities followed at 34.1%. Regular community sponsored recreation and accessible community sponsored recreation were rated as inadequate or fair by almost 72% of the respondents. Special/segregated recreation/social opportunities only fared slightly better with almost 60% rating them as inadequate or fair as well. Availability of accessible recreation opportunities were reported as not available by 28.7%, and somewhat available by 43.3%. Availability of social opportunities in the community were rated as not available by 27.2%, and as somewhat available by 48.2%. Focus group respondents cited *no recreation opportunities available* most often as a recreation/social challenge. Other problems identified include, *limited availability of accessible community-based social and recreation activities, community perceptions, attitudes about persons with developmental disabilities that limit recreational opportunities, transportation issues (e.g., (costs, schedules, availability), and the need for more affordable recreation activities/events.* The majority of respondents shared that had received supports from *communities and organizations that would provide accessible recreation options and support.* Other help received came from *segregated programs that provide recreation programs/activities, and community initiatives that increase community recreation options for persons with developmental disabilities.*

Community Resource/Support Issues:

The most likely type of community resource to be used, not funded directly to serve people with disabilities, were family and friends (60.5%). The least likely type of community resource to be used by people with disabilities was civic organizations (9.7%). The type of community resource reported as most inadequate was also civic organizations (40.4% seen as inadequate). Social organizations were reported as inadequate by 25.9%, and fair by an additional 34.2%. Supports received from family and friends were rated as excellent by 38.2%, and 38.4% as good. Community support received through faith based organizations were rated by over 56% as either good (37.7%), or excellent (18.4%). Overall, 70% of the respondents reported the support they receive from their community as mostly, or somewhat supportive. Focus groups reported receiving community supports most often from *faith-based organizations, and family, friends, and neighbors.* Other supports were identified as *general support of community for persons with developmental disabilities, and other community groups.* It was reported by many that they experienced *good acceptance and support from the community,* while at the same time a smaller number indicated a *little or no acceptance.* Other attitude considerations expressed included the need for *community education and awareness about*

developmental disabilities, more acceptance of people with disabilities and the importance of getting to know people with disabilities and forming relationships with them.

Safety and Quality Assurance Issues

Survey respondents were asked if they were aware any of incidents that affect the health, safety and quality of life of people with disabilities in their community. Of the 737 people surveyed, about 20% were aware of some physical abuse/neglect in their community; 16% were aware of sexual abuse; 21% were aware of some type of financial abuse; and 24% were aware of a human or legal rights violation. Respondents were also asked to share their perception about how the above types of incidents had been handled. Of those responding, the perception of about two thirds was that safety incidents were not handled well, or at all. Because the handling of these types of incidents often requires a degree of discretion, it is important to recognize that respondents perceptions of how these incidents are handled may not necessarily reflect what actually occurred to address them.

Almost 60% saw people with disabilities as being *mostly safe* or *very safe* in their community. Focus group participants discussed ways people with disabilities have been included in community life. The most common theme was through the *support and involvement of community organizations and businesses*. Also cited was the *general acceptance of people with developmental disabilities in the community*. Other ways they have been included is through the *support from faith based organizations that support persons with developmental disabilities in the community*. Respondents also reported that *families and friends advocate for persons with developmental disabilities to be included in the community*. Respondents were asked to identify ways people with disabilities are excluded from community life. *Attitude and lack of understanding of persons with disabilities* was cited most often as the reason for why they excluded from community life. Another way cited was that *individuals are excluded from community activities due to distance, transportation and other accessibility issues*. Respondents were asked to discuss how they were included in planning processes that affect their lives. Many felt that they had been involved planning processes affecting their lives. They also expressed that family/friends support persons to participate in the planning process, and that agency staff, teachers, and school counselors assisted as well.

Satisfaction with Services:

Service coordination was seen as good (40.3%) or excellent (29.8%) by over 70% of the respondents. The quality of provider services/supports was rated as good (40.8%) or excellent (24.1%), by almost 65% of the respondents.